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The Church at the Service of Sick Elderly People: Care for People with Neurodegenerative Pathologies

21-22-23 November 2013

**New Synod Hall
Vatican City**

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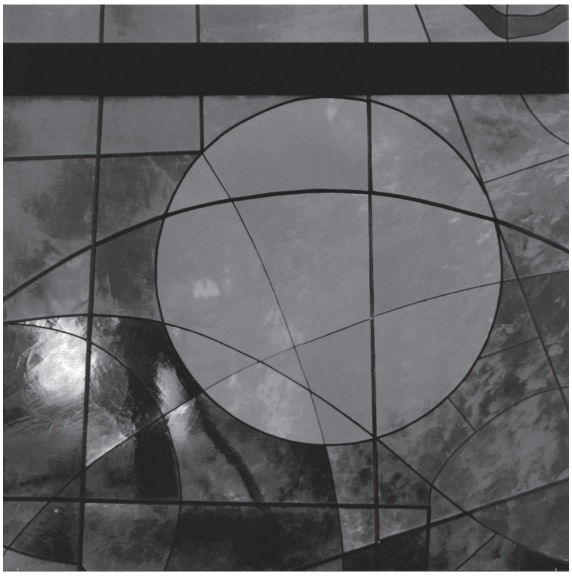

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New Synod Hall
Vatican City

Encounter of Prayer and Reflection of Health-Care Workers with the Holy Father Francis on the Eve of the End of the Year of Faith Held at the End of the Twenty-Eighth International Conference

23 NOVEMBER 2013, PAUL VI HALL

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President of the Pontifical Council for Health Care Workers (for Health Pastoral Care)

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Introduction

H.E. MSGR.
ZYGMUNT ZIMOWSKI
President of the
Pontifical Council
for Health Care Workers,
the Holy See

Your Most Reverend Eminences, Your Most Reverend Excellencies, dear priests, men and women religious. I am very happy to greet the organisers of, and those taking part in, this important twenty-eighth international conference, which has just ended and which has addressed the subject 'The Church at the Service of Sick Elderly People: Care for People with Neurodegenerative Diseases'.

I also greet most cordially the various organisations for sick and suffering people, and in a special way the UNITALSI.

Dearest sick people, thank you for your presence!

The Year of Faith, which was convoked by the Holy Father Benedict XVI, is about to come to an end. During this time 'faith based upon encounter with the risen Jesus Christ can be rediscovered in its wholeness and in all its splendour', the Holy Father wrote in the document *Porta fidei*. All of us, when we meet an important person, feel shivers; here we should ask ourselves: does not the encounter with Christ and his gift of faith give us a new 'shiver', suggesting to us a new direction in our lives? Here, therefore, is a year to foster the joyous rediscovered and renewed witness to faith. The Year of Faith, certainly, is almost at an end, and there remains the impulse that must permeate the whole of our lives today and for the years that God grants us in the future.

In order to have a better understanding of the meaning and the depth of what Pope Francis wrote in his first encyclical, *Lumen Fidei*, on the strength and the light that can come from Faith during suffering (*Lumen Fidei*, 56-59), it is important to contextualise it within the overall argument of this encyclical and in continuity with the encyclicals of Benedict XVI on charity (*Deus Caritas est*) and on hope (*Spe Salvi*), as well as with reference to the extensive reflection on suffering offered by John Paul II in his apostolic letter *Salvifici doloris*.

A first observation on the relationship of faith and suffering, as offered in the encyclical of Pope Francis, relates to the location itself of this analysis in the fourth part of the work ('God Prepares a City for Them') where it is emphasised how faith is not an abstract reality but, rather, is for life and to bring light into all the situations of existence. It 'illumines life and society. If it possesses a creative light for each new moment of history, it is because it sets every event in relationship to the origin and destiny of all things in the Father' (n. 55).

Faith does not distance us from the world and from its real problems. Indeed, it offers a service to build up a humanity and a society where justice, respect for, and the defence of, the dignity of each person, education in social fraternity that seeks the common good, and attention towards and care for the weakest categories, those in conditions of poverty and especial suffering, prevail.

The reference, therefore, to the relationship of faith and suffering is not in the least isolated. Indeed, ‘suffering’ seems to become a ‘setting’ and an ‘experience’ to ask ourselves both about the truth of faith and its illumining force and about the authenticity or otherwise of our human life and our social relationships.

A statement that Benedict XVI makes in his encyclical *Spe Salvi* seems to ring out powerfully: ‘The true measure of humanity is essentially determined in relationship to suffering and to the sufferer. This holds true both for the individual and for society. A society unable to accept its suffering members and incapable of helping to share their suffering and to bear it inwardly through ‘com-passion’ is a cruel and inhuman society’ (n. 38).

But suffering, Pope Francis stresses, is also a place of faith, of hope and of love. A setting where, in the experience of the Apostle Paul (cf. 2 Cor 4:7-12), suffering and weakness itself becomes a setting in which to proclaim and live faith, recognising the presence and the power of God which triumphs over our weakness and is able to give us strength, light and comfort during suffering itself (n. 56).

Even though suffering cannot be eliminated, Christian faith can help us to give it a meaning, and to the point that it can ‘become an act of love and entrustment into the hands of God who does not abandon us; in this way it can serve as a moment of growth in faith and love’ (n. 56).

Faith does not have any explanations to give about suffering but it can give meaning and strength so that it can be lived. ‘Faith is not a light which scatters all our darkness, but a lamp which guides our steps in the night and suffices for the journey’ (n. 57).

For our arduous journey of suffering as well, where God does not leave us alone but walks at our side: ‘To those who suffer, God does not provide arguments which explain everything; rather, his response is that of an accompanying presence, a history of goodness which touches every story of suffering and opens up a ray of light. In Christ, God himself wishes to share this path with us and to offer us his gaze so that we might see the light within it’ (n. 57).

According to a happy phrase of St. Bernard ‘God cannot suffer but He can suffer with’. ‘Man is worth so much to God that he himself became man in order to *suffer with* man in an utterly real way – in flesh and blood – as is revealed to us in the account of Jesus’s Passion. Hence in all human suffering we are joined by one who experiences and carries that suffering *with* us; hence *con-solatio* is present in all suffering, the consolation of God’s compassionate love – and so the star of hope rises’ (*Spe salvi*, n. 39).

Pope Francis ends his first encyclical *Lumen Fidei* with a prayer to Mary, Mother of the Church and Mother of our faith, which can be of help to the sick and suffering, especially at moments of abandonment or death:

Mother, help our faith!
Open our ears to hear God’s word and to recognize his voice and call.
Awaken in us a desire to follow in his footsteps, to go forth from our own land and to receive his promise.
Help us to be touched by his love, that we may touch him in faith.
Help us to entrust ourselves fully to him and to believe in his love, especially at times of trial,
beneath the shadow of the cross, when our faith is called to mature.
Sow in our faith the joy of the Risen One.
Remind us that those who believe are never alone.
Teach us to see all things with the eyes of Jesus, that he may be light for our path. And may this light of faith always increase in us, until the dawn of that undying day which is Christ himself, your Son, our Lord!

Matthew 25:31-46: the Final Judgement

H.E. MSGR. JOSÉ RODRÍGUEZ CARBALLO, O.F.M.
Archbishop Secretary of the CICLSAL, Congregation for Institutes of Consecrated Life and Societies of Apostolic Life, the Holy See

We have heard one of the most important and well-known passages from the Gospel of Mark, indeed, from the gospels. This is the last discourse of Jesus. As is known, the Gospel of Mark presents Jesus as the new Messiah. As Moses did, so Jesus promulgated the law of God. As with the old Law, the new Law given by Jesus contains five books or discourses. The first is the sermon on the mount (cf. Mt 5: 1-7, 27); the last is on vigilance (cf. Mt 2:1-25, 46), in which, indeed, we find the text that we have listened to. The first contains the beatitudes; the last speaks about the final judgement. The beatitudes describe the entrance gates to the Kingdom, listing eight categories of people: the poor, the meek, the afflicted, those who hunger and thirst for justice's sake, the merciful, the pure of heart, the peacemakers and those persecuted because of their love for justice (cf. Mt 5:3-10). The text on the final judgement that we have listened to tells us what we must do to enter the Kingdom: we must welcome the hungry, the thirsty, foreigners, the naked, the sick and prisoners (Mt 25:35-36).

The Christian *diakonia* finds its foundation in this text. The *Catechism of the Catholic Church* cites this text to promote Christian *diakonia* and to give it its due foundation. This text precedes the list of the seven works of mercy, completed by a text from the Book of Tobit which speaks about the burying of the dead (cf. Tb 1:17). This is an important text: one need only think that St. John Chrysostom cites it 170 times in order to justify solidarity towards the poor through reference to this text.

This is the final judgement, thus the most decisive moment for each one of us. This is not a joking matter. We will hear from the Lord himself: 'whatever you did for one of these least brothers of mine, you did for me,' or for mine; 'what you did not do for one of these least ones, you did not do for me.' Five times we have heard the adverbs 'then' and 'when': 'then', that is to say at the end, we will see that the 'when' is now. The fate of 'then' (at the end) is decided 'now', 'at the present time'. The text clearly tells us that at the margins of the 'sacrament' of neighbour there is no road to God. The text has a great Christological force: Christ continues his incarnation in the poor. On the other hand, the text also has a great ecclesiological importance: 'The least ones', says Moltmann, 'can tell us where the Church is'. I believe that the text must centre our attention both in solidarity with the *poor* in a broad sense – who should be identified historically with the disciples, described by the Gospel as the 'least' (*Mt* 10:16, 23, 24:40-42) – but also with all those who need help or who endure penury of any kind, and with faith: in the poor we must find Christ; in their wounds we are called to contemplate the wounds of Christ himself.

In this way the text that we are analysing shows us our faith is not only a question of the 'profession' of revealed truths. It is also a question of a 'profession of belonging', that is to say a question of communion, of solidarity, which one enters through faith; a question of a covenant, and familiarity, with the poorest. There is no salvation outside communion.

Let us go back to Matthew. Chapter 25, the location of our text, contains three 'gradual' narratives on what should be done 'now' in view of the 'end': ''the oil should be purchased now' (vv. 1-13), and this involves 'doubling' the gift of love that has been received (vv. 14-30) by loving the Lord in his least brethren (vv. 31-46). The judgement that the king will make about us 'now' is the same that we now make about the poor. In reality, it is we ourselves who judge ourselves: by welcoming or rejecting the king in the persons of the poor. He will do nothing else but observe what we have done. He tells us this beforehand so as to out open our eyes to we are doing now.

This passage, which is splendid and unique, is a summary of the theology of Matthew: we are judged on the basis of what we do to others (7:12). Every other person is always the other. The first commandment, indeed, is equal to the second (22:39), because the Lord himself has made himself our neighbour and is always with us (28:20) as the Son of man (24:30) who has the face of all the poor of the earth. We will be judged on the basis of our love for the least and the weakest, in whom we are called to see Christ himself (Francis and the leper). Whether we are 'blessed' or 'accursed' depends on the love that has been given or denied to our brethren who live in need and through whom the Lord comes to visit us. The love that we have towards the other is love for God: I fulfil myself as a son by living as a brother. All of the law, indeed, comes down to loving the Lord and our neighbour with the same love. We cannot say that we love God, whom we do not see, if we do not love the brethren that we do see.

To this we can add another observation: we can love God in the other only if we feel loved by God. To isolate the commandment of love for the least from the experience of the love of God who made himself the last for me is to make it a meaningless principle, an ideology that is incapable of generating positive behaviour.

To end this paper of mine, we can say that the final judgement, like the whole of the eschatological discourse, sends us from the future to the present. The purpose of man is to become like God. The error of Adam was not wanting to become like Him (Ge 3:5) but not knowing who He was. One becomes like God by loving, because He is love. Jesus is always with us (28:20), like the poor (26:11), like the least of our brethren. The Church, in her love for the least, loves her Lord; and she knows that it is not she who saves the poor but that it is the poor who saves her.

Questions to be Reflected on:

If the hour of judgement were to take place now, where would I sit: on the right amongst the blessed or on the left amongst the accursed?

What is my behaviour towards the poorest: is it an attitude of 'I don't care at all', an attitude of philanthropy, or an attitude of faith, managing to see in them the poor and suffering Christ?

Can I do more than what I am doing for the 'least'? ■

Address of the Holy Father Francis

PAUL VI AUDIENCE HALL - SATURDAY, 23 NOVEMBER 2013

Dear Brothers and Sisters,

Thank you for your welcome! I cordially greet you all.

Today I would like to repeat that the elderly have always been and still are protagonists in the Church. Today more than ever the Church must set an example for the whole of society that, despite their inevitable and sometimes grave "ailments", the elderly are always important; indeed, they are indispensable. They carry the memory and wisdom of life to hand down to others, and they participate fully in the Church's mission. Let us remember that, in God's eyes, human life always retains its value far beyond any discriminating vision.

The increased life expectancy which developed over the course of the 20th century has entailed that a growing number of people are facing neurodegenerative diseases, which are often accompanied by a deterioration of the cognitive capacities. These diseases push the socio-health care world both to the horizons of research, and to those of assistance and care in social facilities, as well as in the family, which remains the privileged place of warmth and closeness.

The provision of adequate assistance and services which respect the dignity, identity and needs of patients is important, but the support of those who assist them, whether family members or healthcare professionals, is also important. This is only possible within the context of trust and within an atmosphere of a mutually respectful relationship. Lived in this way, care becomes quite an enriching experience, both professionally and humanly; otherwise, it becomes all too similar to cold, basic "physical protection".

It therefore becomes necessary to be committed to a form of assistance that, alongside the traditional biomedical model, offers spaces of dignity and freedom, far, far away from closure and silence, that torture of silence! Silence is so often transformed into torture. People who live in assisted care are often surrounded by this sense of enclosure and silence. Within this perspective, I would like to stress the importance of the religious and spiritual aspect. Indeed, this is a dimension that remains vital even when cognitive faculties have been reduced or lost. It is a matter of implementing a special pastoral approach in order to accompany the religious life of elderly patients with serious degenerative diseases in various forms, to ensure that their minds and hearts do not interrupt their dialogue and relationship with God.

I would like to conclude by greeting the elderly. Dear friends, you are not only recipients of the good news of the Gospel message; in virtue of your Baptism you shall always be its heralds in the truest sense. Each day you can live as witnesses of the Lord, in your families, in your parishes and in your habitual meeting places, by making Christ and his Gospel known, especially to the younger generations. Remember that it was two elderly people who recognized Jesus in the Temple and proclaimed him with joy, with hope. I entrust all of you to the protection of Our Lady, and I thank you from my heart for your prayers. Now, all together let us pray to Our Lady for all healthcare workers, for the sick, for the elderly and then let us receive the blessing (*Hail Mary*...). ■

THURSDAY 21 NOVEMBER

OPENING ADDRESS

The Concern of the Church for Sick Elderly People: the Magisterium of Recent Years

H.E. MSGR.
ZYGMUNT ZIMOWSKI
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Pontifical Council
for Health Care Workers,
the Holy See

The Catholic Church has always dedicated greater care and commitment to sick elderly people.[1] With the recent transformations of society, in particular in developed countries, this care has taken place with concern and with specific pastoral action because of the frequent situations of physical and moral suffering of sick elderly people and the human and Christian duty to accompany them until their deaths, at the last stage of life, a death that should be – as much as this is possible – consciously faced up to, serenely accepted and lived through, in the light of hope. As a consequence, in recent times the Magisterium of the Popes has been very much addressed to sick elderly people.

In opposition to contemporary society, which tends to see the ageing of the population as a grave economic and social problem, the Church, through the encyclical letters, speeches, allocutions and messages of this papal Magisterium, sees the greater presence of more sick elderly people in the world not as an increasingly intolerable 'burden' but, rather, as a 'blessing',[2] and this because these people, encouraged by the pastoral activity of the Church, are faithful, day by day, to their specific vocation, in a humble and trusting acceptance of the will of our heavenly Father.

The observations, reflections and exhortations that have been developed in this papal teaching on sick elderly people can be categorised in the following way:

– The problems of sick elderly people today.

– Suffering and malaise in sick elderly people.

– The spiritual lives of sick elderly people and the pastoral mission of the Church in this field.

– Sick people at the end of their lives and accompanying them until death.

– The Church's message to sick elderly people.

I. THE PROBLEMS OF SICK ELDERLY PEOPLE TODAY

A. Eternal Features

Times of the 'weakening of physical strength, of less vivacity in the spiritual faculties, of a *steady detachment* from activities to which people were previously attached' (John Paul II, 1982),[3] the 'third' and 'fourth' ages of human life are also times of illnesses that debilitate and an increasing state of being an invalid which are derived from such illnesses. At the same time, these third and fourth ages, which are marked by the 'prospect of separation because of the departure for the life beyond' (*ibidem*), constitute the last part of the pilgrimage on earth, the step that is perhaps the most important one of this life, where a human being can prepare himself or herself in a serious way, engaging, if possible in serenity, in that spiritual work that is indispensable for the welcome by this 'sister' who takes us to the Father (John Paul II, 'Letter to the Elderly', 1999, n. 15). [4]

B. The Welcome in Contemporary Society for its Sick Elderly Members

Old age, the illnesses associated with it and death are 'component parts of life' that constitute at the same time a strong appeal to the 'world of human love' as against an invasive 'culture of death'[5] which is generated by a cold, technical, utilitarian anti-human world – a world more of having than of being. Thus it is that one can measure the level of spiritual riches and humanity of such a society by the way in which from within it there flows disinterested love for elderly people: 'more broadly, one can state that the way in which a civilisation recognises old age and death as a component element of life, and the way in which it provides necessary help to its elderly members to live out their deaths, are a criterion that decides the respect that it has for man' (John Paul II, 'Message to the Participants at the World Assembly on the Problems of Ageing, 22 July 1982').

Using this criterion of assessment, one can say that today society, especially in the most developed and richest countries, does not offer such a respectful and warm welcome to its older members, especially when they are sick, weakened or disabled. This is due to a conjunction of factors, amongst which the ageing of the population in these countries and the competitive character of a liberal and individualistic society where it is the efficient individual who is capable of working and producing that matters.

C. The Ageing of Populations

The Pontifical Council for the Laity, in the introduction to is documentary note of the year 2000, 'The Dignity of Older People and their Mission in the Church and the World', rightly refers to the demographic collapse generated by the spread of contraception and the decriminalisation of abortion in the world starting in the 1960s which today is common to all developed countries and beyond, and which has brought about the accelerating ageing of the populations in these countries: 'The prolongation of average life expectancy, and the sometimes dramatic decrease in the birth rate, have given rise to an unprecedented demographic transition: the age pyramid that existed less than half a century ago has literally been turned upside down. The number of older people is constantly increasing, while that of the young is constantly decreasing. Starting out from the countries of the northern hemisphere in the 1960s, the phenomenon has now spread to those of the southern hemisphere, where the ageing process is even more rapid' (The Pontifical Council for the Laity, 'The Dignity of Older People and their Mission in the Church and the World', 1998).[6]

The increase in the 'passive' part of the population – the elderly – at the same time as the 'active' part, on which the economy is based – constantly decreases, has produced a 'silent revolution' which goes well beyond demographic data and raises grave problems of an economic, social and cultural character.[7] This imbalance in part explains the 'marginalisation or 'social euthanasia' that is suffered by many sick elderly people today.

D. The Frequent Negative Portrayal of Old Age

Connected with this phenomenon of the increase in the number of elderly people in the population, there is another factor which makes this period of human existence not seen in positive terms. I am referring here, in particular in the mass media, to the positive value bestowed upon human life only when it is lived in full autonomy, that is to say when we are young, in good health, 'in full possession of our strength' (John Paul II, 1982),[8] without economic problems and with a good job, situations, in fact, which rarely come together in the real world.

It follows from this that 'many of our contemporaries see' old age as 'nothing but an unavoidable and burdensome decline' (The Pontifical Council for the Laity, 'The Dignity of Older People and their Mission in the Church and the World', 1998).[9]

Thus old age, which was previously seen, down the centuries, as a period of wisdom and a source of valuable advice (John Paul II, Letter to the Elderly, n. 9, 1999),[10] as something to be respected and honoured, today is seen negatively as a 'period of decline', of 'human and social inadequacy', from which nothing can be expected (The Pontifical Council for the Laity, 'The Dignity of Older People', 1998).[11]

Furthermore, another factor acts to foster this rather negative portrayal of old age on the part of public opinion – that mentality 'which gives priority to immediate human usefulness and productivity. Such an attitude frequently leads to contempt for the later years of life, while older people themselves are led to wonder whether their lives are still worthwhile' (John Paul II, 'Letter to the Elderly', 1999, n. 9).[12]

E. Weakened Elderly People are Seen as an 'Intolerable Burden'

The 'utilitarian and subtly inhuman mentality' which leads today to elderly people being despised obviously has a negative impact on the assessment of this person when he or she also falls ill, is weakened or is an invalid: 'How often do those who suffer because of age or illness perceive that the environment that surrounds them sees them as useless people, reduced solely to being a burden for others' (John Paul II, 'Address to the Elderly and the Sick, St. Stephen's Basilica, Budapest, 20 August 1991', n. 2).

This mentality leads the sick elderly person to be seen as an 'intolerable burden' who threatens the wellbeing of society: 'Here we are faced with one of the more alarming symptoms of the "culture of death", which is advancing above all in prosperous societies, marked by an attitude of excessive preoccupation with efficiency and which sees the growing number of elderly and disabled people as intolerable and too burdensome' (John Paul II, *Evangelium Vitae*, 1995, n. 64).[13]

In this attitude of mind it is the very value of the life of the sick elderly person that is in the last analysis called into question, little by little leading public opinion to accept first the marginalisation of such people and then, when this happens, their active elimination: 'These people are very often isolated by their families and by society, which are organised almost exclusively on the basis of criteria of productive efficiency, according to which a hopelessly impaired life no longer has any value' (*Evangelium Vitae*, 1995, n. 64).[14]

F. The Marginalisation of Sick Elderly People

The development of this phenomenon of the marginalisation of elderly people is 'relatively recent'. It 'has found a fertile breeding ground in a society that cultivates nothing but material success and the glossy image of perennial youth, to the virtual exclusion of those who no longer possess these requisites' ('The Dignity of Older People', 1998, n. 3).[15] This marginalisation often happens when there is illness which in its turn leads this person to be placed in an institution. The result of this is a 'progressive removal of older people from their own family and social environment' which consigns 'many elderly people to the fringes of the community and civil life' ('The Dignity of Older People', 1998, n. 3). [16]

Often it is the elderly person himself or herself who begins to marginalise himself or herself, despising himself or herself and folding in on himself or herself when he or she feels ignored or treated as useless. [17]

'The most painful dimension of this marginalisation, however, is the lack of human relations. Older people suffer not only by being deprived of human contact, but also from abandonment, loneliness and isolation' (The Pontifical Council for the Laity, 'The Dignity of Older People', 1998, n. 3).[18] 'Very often', observed Benedict XVI, 'one hears of the suffering of those who are marginalised, who live far from their home or are lonely' (Benedict XVI, 'Visit to the 'Viva gli Anziani' Home, November 2012').[19]

The elderly person is thus relegated to 'a loneliness that can be compared to an authentic social death' (John Paul II, 'Letter to the Participants at the World Assembly on Ageing, 3 April 2002').[20]

More recently, during his apostolic visit to Brazil, Pope Francis, to describe this suffered marginalisation of elderly people employed the strong phrase 'cultural euthanasia': 'They exclude the elderly, obviously. You could easily think there is a kind of hidden euthanasia, that is, we don't take care of the elderly; but there is also a cultural euthanasia, because we don't allow them to speak, we don't allow them to act' (Pope Francis, 'Meeting with Young People from Argentina at the Cathedral of San Sebastian, Brazil, 25 July 2013').

G. Elderly People and the End of Life

1. Recent changes

The conditions in which sick elderly people now die have changed a great deal in recent years under the joint impact of the reduction of the family to a nuclear level, the increase in the number of elderly people who die in institutions or hospitals, and the marginalisation of many of these people, who, indeed, live and die in a painful loneliness.[21]

What has also changed is the attitude of medical doctors to death and they often encounter difficulties in finding a wise middle way between abandoning the patient, a pharmacological acceleration of the end of life process, or the artificial maintenance of his or her life,[22] a process which is often called 'exaggerated treatment'.[23]

2. The temptation of euthanasia

These changes mean that 'elderly people today, less prepared for suffering and death, worried both by the prospect of having to suffer and by the other prospect of seeing themselves kept alive with modern life support systems, can easily fall prey to the temptation of euthanasia, which is seen as a 'liberation'' (Pope Francis, Address of 23 November 2013, Rome').

This temptation is increased today by the culture in which elderly people are immersed and which assesses life solely in terms of pleasure and material wellbeing: in this approach, death is seen as a 'liberation' and euthanasia is seen as a 'good' way of achieving such liberation: 'When the prevailing tendency is to value life only to the extent that it brings pleasure and well-being, suffering seems like an unbearable setback, something from which one must be freed at all costs. Death…becomes a "rightful liberation" once life is held to be no longer meaningful because it is filled with pain and inexorably doomed to even greater suffering' (John Paul II, *Evangelium Vitae*, n. 64).

In contemporary secularised and materialistic society, given that the profound meaning of life has been lost, and thus the meaning of death as well, medical or paramedical personnel who take care of sick elderly people, given their precariousness as regards life, their malaise and their suffering, have the tendency not to find a meaning in the existences of such people: 'If it is true that human life in every phase is worthy of the maximum respect, in some sense it is even more so when it is marked by age and sickness… One may ask: does a human being who moves toward a rather precarious condition due to age and sickness still have a reason to exist? Why continue to defend life when the challenge of illness becomes dramatic, and why not instead accept euthanasia as a liberation? Is it possible to live illness as a human experience to accept with patience and courage?' (Benedict XVI, 'Address to those Taking Part in the Twenty-second International Conference of the Pontifical Council for Health Care Workers, 17 November 2007'). [24]

When human life is only assessed on the basis of criteria of 'efficiency' and disabled people come to be seen as burdens, in their families as well, then the temptation of euthanasia grows, and the same may be said of a hurried 'deep sedation', within the context of 'palliative care', on the part of both the family relatives and the care personnel: 'In this context the temptation grows to have recourse to euthanasia, that is, to take control of death and bring it about before its time, "gently" ending one's own life or the life of others' (John Paul II, *Evangelium Vitae*, n. 64).

3. The 'Culture of Waste'

The Holy Father Francis, during his recent visit to Brazil, rightly defined this 'culture of death' which leads to proposing euthanasia or the terminal palliative hurried sedation of elderly people as the 'culture waste'. This is what the Pope said to journalists: 'We have become somewhat accustomed to this throwaway culture: too often the elderly are discarded!... We must rid ourselves of this habit of throwing away' (Pope Francis, 'Interview with Journalists, 22 July 2013').

More recently, when addressing a group of obstetric doctors, Pope Francis continued his observations on the contemporary 'elimination' of sick elderly people in institutions or rest homes: 'A widespread mentality of the useful, the "culture of waste" that today enslaves the hearts and minds of so many, comes at a very high cost: it asks for the elimination of human beings, especially if they are physically or socially weaker'. [25]

II. SUFFERING AND MALAISE IN SICK ELDERLY PEOPLE

The question of suffering has occupied an important place in the teaching of the Magisterium of the Church in recent years. Indeed, the illness that afflicts elderly people often comes to aggravate a situation of suffering that is already present, a 'situation of inner malaise, of increasing suffering, accompanied by loneliness and discomfort'[26] brought about by the frequent marginalisation of these people and to the reduction of their physical autonomy. It is not easy for the people involved to accept such a set of difficulties.

Taking into consideration this situation of the deterioration of the physical and mental health of sick elderly people and their frequent marginalisation and loneliness, one easily deduces that the greatest and most urgent problem raised by these people today for society, and thus for the Church as well, is that of their suffering. This is suffering not only of the body but also of morale, where feelings of uselessness, being abandoned, physical deterioration, marginalisation and loss of autonomy are combined with physical pain and the malaise of illness to create a severe trial, that of the 'total pain' which was well described by Cecily Saunders (1918-2005), the valorous initiator of palliative care. The Church has addressed this problem down the centuries through her meditation on the mystery of the Passion of Jesus. The Holy Father John Paul II developed a deep analysis on the question of human suffering in the light of his own experience. He expressed his thought on the subject on the occasion of numerous speeches and meetings with groups of elderly and sick people, and he consecrated to this subject his apostolic letter *Salvifici Doloris* on the 'Christian meaning of human suffering' (11 February 1984). In these statements the Blessed John Paul II amply recognised the often intolerable character of the suffering of elderly people, but at the same time he tried to demonstrate the good that can accompany such a situation both for sick people themselves and for the people who care for them, for the Church, and also for the world.

The papal Magisterium clearly discerns two aspects of the suffering that is experienced by sick elderly people and to which separate responses should be given: the first concerns only physical pain and raises the question of the licit character, or otherwise, of the use of pain killers to alleviate such suffering; the second concerns the suffering of a sick elderly person seen in his or her spiritual, mental and somatic whole, as 'total pain', to which the Magisterium has devoted great attention.

A. The Use of Pain Killers

The teaching of the Church on the meaning of human suffering, in the light of the sufferings of Christ, does not oblige Christians to accept pain without having recourse to the use of pain killers. Here the question was amply clarified by Pius XII in his 'answers to three religious and moral questions on analgesia' raised by Prof. Piero Mazzoni on the occasion of the tenth national congress of the Italian Society of Anaesthesia which was held in Rome on 15-17 October 1956.

There are three answers which correspond to the three levels of anaesthesia: the licit character of analgesia to alleviate physical pain; the licit character of alleviating pain when the risk is run of shortening life; and the conditions in which one can deprive the dying of consciousness.

The first question related to whether analgesia was licit and Pius XII answered as follows: 'if no other means exist and if, in the given circumstances, this does not prevent the performance of the other religious and moral duties: yes'.[27]

The second question related to whether it is licit to use pain killers with patients who cannot be operated on or are incurable, even though this could shorten their lives. Pius XII gave the following answer: 'If there exists no direct causal connection, placed by the will of the involved or by the nature of things (the case would be, between the use of drugs and the shortening of a life: if the suppression of pain could only be obtained through a shortening of a life); if, on the contrary, the administration of the drugs generates in it itself two distinct effects, on the one hand the alleviation of pain, and on the other the shortening of the life, then it is licit'.[28]

The third question related to whether it was licit to end the consciousness of a person through analgesics in the case of a dying person. The answer of Pius XII to this third question was more restrictive than his previous two answers: 'it is not right to deprive the dying person of consciousness without a serious reason'.[29]

As a consequence: 'Anaesthesia used when death draws near, with the sole aim of enabling the patient to avoid a conscious end, would be not already a notable advance of modern therapy but a truly deplorable practice' (Pius XII, 'Three Religious and Moral Questions Concerning Analgesia, 24 February 1957').[30]

Pius XII's request that a dying person should be allowed consciousness is based upon the need of the dying person 'to meet his or her moral and family obligations' and to prepare himself or herself in full consciousness 'for the final encounter with God'.[31]

The 'Declaration on Euthanasia', *Iura et bona*, of the Sacred Congregation for the Doctrine of the Faith (5 May 1980), took up the answers given by Pius XII in order to emphasise the legitimacy of the use of pain killers in the case of pain, even if such a use is followed by 'semi-consciousness and reduced lucidity'.[32]

While observing that 'praise may be due to the person who voluntarily accepts suffering by forgoing treatment with pain-killers in order to remain fully lucid and, if a believer, to share consciously in the Lord's Passion', John Paul II, in his encyclical letter *Evangelium Vitae*, believed that such '"heroic" behaviour cannot be considered the duty of everyone' (John Paul II, *Evangelium Vitae*, n. 65).

B. The Spiritual Pathway of a Suffering Sick Elderly Person

Suffering that places on the shoulders of sick elderly people its physical and moral burden, brings to the minds of those who suffer the question of meaning: 'Your fate and your tribulation often weigh heavily on your shoulders. Who of you has never been tempted to ask whether their troubles, their tribulations and their tiredness were deserved and had a meaning' (John Paul II, 'Homily to the Elderly and the Sick, Salzburg Cathedral, 26 June 1988', n. 2).

This question about meaning also provokes in the consciousness of the believer the second fundamental question: 'Why does God allow me to suffer? Without the light of faith such a question remains without a satisfactory answer'.[33]

This is the moment when suffering can make a person draw near to the Lord. However it can also lead to despair and to a person to fold in on himself or herself.[34]

Whereas closing in on oneself can lead a sick person to return to being insensitive to other people in a despair without an exit or light,[35] and make difficult if not inoperative every attempt at accompanying, openness to other people and to God, moved by an experience of the limits of the creature, makes accompanying fertile and leads the patient to active hope, that is to say to carrying out his or her vocation as a sick elderly person.[36]

One is dealing, therefore, in the case of a sick elderly person, of managing to 'recognise the hand of God when tested', when 'He knocks at the door of hearts'.[37] In discovering 'through the experience of our frailty' the 'loving presence of God' in suffering, a sick elderly person is led 'to cry out' his or her pain 'towards He who alone can give us true relief'. Thus suffering can become a 'school of felt, insistent and trusting prayer'.[38]

Even when a patient has taken up the path of leaning on the Lord in a movement of full trust and self-abandonment to His will, grave periods of discouragement can take place, 'when the question of the reason for his life, precisely because he feels uprooted from it, is raised'.[39] Through the succession of these stages of overcoming and discouragement a sick elderly person, encouraged and supported by those who accompany him or her, can in the final instance reach this 'encounter with God' in which 'ineffable words of hope' are also addressed to the 'most deeply wounded heart'.[40]

The 'certainties of hope' for those who have the joy of believing can transform the last journey of a sick elderly person into an authentic 'Via Crucis' in the presence of Christ the Redeemer 'who followed his painful pathway of the cross before the radiant dawn of Easter'.[41] In accompanying the sick elderly person in this way 'on the last stage of his or her earthly life', Jesus 'gives courage to hearts' and 'restores souls'.[42]

C. The World of Suffering Calls on the World of Human Love

The emphasis placed in recent years on the relief of physical pain while awaiting death through palliative care has somewhat led us to lose from sight the masterful insight of Cecily Saunders about 'total pain'. Without losing sight of the primary duty to make physical pain disappear through the use of pharmacology, thereby providing the patient with his or her freedom, Cecily Saunders included in her fight against total pain the accompanying of the sick person, accompanying at a human level, of a heartfelt character, by nurses trained in this role, and spiritual accompanying by a person sharing the religion or the spiritual opinions of that sick person: chaplains, rabbis, muftis or others. Such an accompanying can be absent in services of palliative care in non-religious institutions. When addressing a group of elderly people and sick people in Callao (Peru) in 1985, John Paul II rightly observed on this subject: 'technical services and health care' 'are not sufficient' to reduce the suffering of a sick elderly person, even when engaged in with 'diligent professionalism'. One must also have 'the affectionate presence of those that he or she loves and his or her friends'. This is the 'spiritual medicine' that 'restores love to life and persuades people to fight for it'.[43]

Faced with the harsh and cold world of the technical character and efficiency of contemporary society, which is not able to alleviate the sufferings of elderly people, these sufferings become an appeal to another world, the world of human love, the only instrument that is able to heal the wounds in the souls of elderly people. This is a disinterested love that 'flows from the heart' of the human person when he or she allows himself or herself to be invaded by 'compassion', as was the case with the Good Samaritan of the famous parable: 'Broad sectors of the technological civilisation have perhaps dreamed of a hard and almost insensitive man, made for work and production… The world of human suffering unceasingly calls for, so to speak, another world: the world of human love; and in a certain sense man owes to suffering that unselfish love which stirs in his heart and actions' (John Paul II, *Salvificis doloris*, n. 2; John Paul II, 'Meeting with the Sick and the Elderly, Callao, Peru, 4 February 1985', n. 2.).

It is not therefore a secondary fact in the Christian approach and in the humanitarian approach that the suffering of sick elderly people, experienced in the loneliness of a hospital bed, can, in the frequent emotional desert of a healthcare world that preaches, instead, stoic insensitivity to its workers, bring forth gratuitous love. On this point John Paul II, during a celebration of the Word for sick and elderly people in the cathedral of Salzburg, made this keenly-felt observations which echoed the parable of Jesus: 'Dear brothers and sisters! Certainly there will always be people who will pass you by uncaring and indifferent. They will make you feel insignificant and useless. But be certain that we need you! The whole of society needs you! You continually call on your neighbours about the deep meaning of human existence. You stimulate their solidarity, and test their ability to love' (John Paul II, 'Address at the Celebration of the Word for Sick and Elderly People, Salzburg Cathedral, Sunday, 26 June 1988', n. 6).

D. The Redemptive Meaning of Human Suffering

'For a Christian', suffering especially suffering at the end of a person's life, 'is not a purely negative fact, rather it is associated in a contrary way with high religious and moral values, and thus can be wanted and sought' (Pius XII, 24 February 1957)[44]: it is a part of the salvific plan of God. It is participation in the Passion of Christ, a way of purification and reparation.

As early as 1957 Pope Pius XII, asked by a group of medical doctors and anaesthetists about the use of analgesia, answered that pain borne as 'acceptance of the cross' had 'meaning in the contemporary economy of salvation'.[45] Although for a Christian there does not exist a duty or obligation to want pain for its own sake, Pius XII went on, he saw it is a varyingly suitable instrument, according to the circumstances, to the goal that is sought.[46] In an allocution to the 'Centre for the Volunteers of Suffering' (7 October 1957), Pius XII described – to the group of sick people and chronically disabled people that he had met – the pain that they suffered as a powerful instrument of salvation for the whole world that completed the Passion of Jesus.[47]

The Declaration *Iura et Bona* on euthanasia of the Congregation for the Doctrine of the Faith of 5 May 1980 emphasised in identical terms this Christian doctrine on suffering as participation in the Passion of Jesus and thus in redemption.[48]

However, it was the thought of John Paul II that developed in the most incisive and penetrating way this subject of the redemptive meaning of human suffering. His point of departure and theological reference point in Holy Scripture was verse 24 of the first chapter of the Letter to the Colossians: 'Now I rejoice in my sufferings for your sake, and in my flesh I am filling up what is lacking in the afflictions of Christ on behalf of his body, which is the church' (Col 1: 24).[49]

When reflecting on this verse in the encyclical letter *Salvifici Doloris*, John Paul II tells us that: 'Christ has in a sense opened his own redemptive suffering to all human suffering. In so far as man becomes a sharer in Christ's sufferings – in any part of the world and at any time in history – to that extent *he in his own way completes* the suffering through which Christ accomplished the Redemption of the world' (*Salvifici Doloris*, 1984, n. 24).[50] Thus 'Every man has *his own share in the Redemption.* Each one is also *called to share in that suffering* through which the Redemption was accomplished…In bringing about the Redemption through suffering, Christ *has* also *raised human suffering to the level of the Redemption.* Thus each man, in his suffering, can also become a sharer in the redemptive suffering of Christ' (*Salvifici Doloris*, 1984, n. 19).[51]

John Paul II was not satisfied with proclaiming the salvific character of human suffering as participation, in the space of the Church, the body of Christ, in the sufferings of Christ, but he went beyond this, proclaiming the 'Gospel of Suffering', that is to say 'the revelation *of the salvific power and salvific significance* of suffering in Christ's messianic mission and, subsequently, in the mission and vocation of the Church' (*Salvifici Doloris*, n. 25).[52] By this phrase the 'salvific power' of suffering, John Paul II meant 'Down through the centuries and generations it has been seen that *in suffering there is concealed* a particular *power that draws a person interiorly close to Christ,* a special grace' (*Salvifici Doloris* n. 26).[53] 'When God permits us to suffer because of illness, loneliness or other reasons associated with old age, he always gives us the grace and strength to unite ourselves with greater love to the sacrifice of his Son and to share ever more fully in his plan of salvation. Let us be convinced of this: he is our Father, a Father rich in love and mercy!' (John Paul II, *Letter to the Elderly*, 1999, n. 13).[54]

This 'salvific power' of suffering, as described by John Paul II, has two consequences. Firstly, a sick elderly person who suffers, in agreeing to do the will of God, becomes a source of grace and of spiritual light for all those people who are around him or her. 'Those who suffer seeking to do the will of God are useful to their neighbours. Even though impeded in external activity, even if isolated in loneliness, they radiate around them a wave of spiritual light on which many other people can draw' (John Paul II, 'Address to the Elderly and the Sick, St. Stephen's Basilica, Budapest, 20 August 1991', n. 3).

Secondly, isolated in his or her hospital bed, and abandoned by society and also by his or her family, an elderly person contributes, through his or her serenely accepted suffering, to the work of redemption of Christ, for the salvation of the world:[55] 'Brothers and sisters, when after a day marked by afflictions and pains, evening arrives, think that Jesus Christ is at your side, he is looking at your face and there expresses his gratitude, because you have persevered with in him in suffering for the salvation of the world' (John Paul II, 'Address to the Elderly and the Sick, St. Stephen's Basilica, Budapest, 20 August 1991', n. 4.).

The result of this is that 'pain, ageing and death itself acquire an immense value because they are associated with…the Passion and the death' of the Lord.[56]

E. The Witness of those who Suffer

This mysterious participation of suffering people in the redemption of the world, and the witness of the work of grace in their souls, which is expressed in the joy and the patience of sick elderly people despite their pain and infirmity, means that sick elderly people who have opened to the love of God become effective preachers of the gospel, witnesses to the 'liberating power of God'.[57] John Paul II spoke here about a 'teaching chair of witness' 'which is that much more convincing the more silent it is' which illness is, when a person who suffers draws 'from his faith' the strength to go on.[58]

III. THE SPIRITUAL LIVES OF SICK ELDERLY PEOPLE AND THE PASTORAL MISSION OF THE CHURCH IN THIS FIELD

A. The Components and the Tendencies of the Spiritual Lives of Sick Elderly People

Through reflection on suffering and in trying to define in a better way what the pastoral care of the Church for sick elderly people should be, the pontifical Magisterium of recent years has highlighted a series of characteristics of the spiritual lives of these people which allow us to speak about a 'special vocation'.

It is clear that the spiritual life in question starts with affliction, it is lived in affliction and it is conditioned by affliction. It is in physical, moral and spiritual suffering that a sick elderly person subjected to pain, to growing weaker, and to the loss of autonomy and loneliness because of illness can rediscover and recognise, in the deep darkness of the affliction and on the threshold of hopelessness, the loving presence of the Lord who is living his passion. One is not, therefore, dealing with a stable system of spiritual life that is acquired at the end of life but, rather, of a journey, which is often difficult, with steps of light and falls into the darkness of the soul which leads a person to detachment, opens him or her to transcendence, and leads him or her, gradually, to the light of hope.

1. A deeper need for the presence of God

The spiritual life of an elderly person is not born, however, in a vacuum, under the sole impulse of suffering. Indeed, it has already been prepared for by the spiritual development of that person when he or she entered old age, which led this person, still vigorous, to draw near to God: in this movement of the soul of the elderly person, faith tested during an active life clearly matters, but also at work is the 'experience accumulated down the years' which 'leads an elderly person to understand the limits of the things of this world' and 'to feel a deeper need for the presence of God'. The 'disappointments experienced' that 'have taught him or her to place his pr her trust in God'.[59]

There is no doubt that there is a grace of openness to transcendence which is specific to the life of the soul of elderly people. Their religious practice, which is often intense, bears witness to this, and it is persevering despite the physical difficulties. Their capacity for abundant and long prayer, despite the tiredness of their bodies and their souls, also bears witness to this.[60]

2. Suffering, however, leads to a doubting of the words of Jesus

The entrance of an elderly person into the regime of suffering when illness arrives changes this spiritual approach which hitherto had appeared very stable, almost a habit. Physical pain, separation from loved ones, the situation of extraneousness when he or she finds himself or herself in a hospital bed, more or less abandoned to himself to herself, a lack of affection, of human warmth, can throw the person towards the abyss of despair. Furthermore, there is often added a disorientation in time and space, with a clouding of the senses, which closes the mind to all hope. 'God can seem far away; life can become a heavy burden'.[61]

3. The risk of fatalism

The spiritual life of such a person is threatened by another 'slippery slope', the invasion 'of a certain fatalism': 'in such cases, suffering, disabilities, illnesses, the losses inseparable from this phase of life, are regarded, if not as divine punishments, at least as signs of a God who is no longer benevolent' (The Pontifical Council for the Laity, *The Dignity of Older People*, 1998, n. 4).[62]

B. The Response of the Church

1. Spiritual healing

The situation of mental confusion and of heavy physical and spiritual suffering of sick elderly people makes difficult, if not even vain, the spiritual accompanying that is offered habitually to sick adults. This is a matter, therefore, of passing through the barrier of confusion and hopelessness in order to establish with the person involved a primary relationship and bring him or her to what John Paul II called 'spiritual healing', that is to say remembering the events of the past in order to lead that person to a 'correct assessment' of his or her situation and 'of the ways in which God works through human weakness as well as through human virtue'.[63] This reflecting on the past, which is habitual in elderly people, can in the case of illness, on the edge of despair, have the character of an authentic therapy.

2. Purifying fatalism

When illness leads a sick person to doubt the goodness of God and to search in his or her past life for events to explain what is interpreted as a punishment of God, the person who provides spiritual accompanying to this elderly person has 'the responsibility to purify this fatalism by helping to develop the religious faith of older people and by restoring a horizon of hope to it'. This is a matter of 'overcoming', through catechesis suited to the situation, 'the image of a wrathful God', to lead the older person to discover the God of love' (The Pontifical Council for the Laity, *The Dignity of the Older Person*, 1998, n. 4).[64]

3. Bringing a sick elderly person to the sacrament of reconciliation

After opening the window of dialogue with a sick elderly person, thank to the process of remembering and of thinking about the past times of his or her life, and after also guiding this person towards discovery of the God of love, the most important stage in this accompanying comes with the invitation to the sacrament of reconciliation. Indeed, the person who is visited by the person who provides spiritual accompanying frequently asks for this sacrament, together with receiving, subsequently, the Eucharist. This request is at the present time facilitated by the fact that amongst 'its unique challenges and invitations', the 'spirituality' of such a person is marked by 'the call to reconciliation that confronts the elderly in the evening of life'.[65]

If the sick elderly person still has the approach that his or her illness is a punishment of God, remembering his or her sins could lead him or her again to discouragement. It is here that preparing him or her well for this sacrament, carried out through accompanying, should allow the person concerned to experience at a deep inner level the forgiveness of God, 'proof of His faithful love for us'.[66]

The sacrament of reconciliation 'plays an important part' in the healing process referred to by John Paul II: 'In this sacrament, reconciliation with God, with the Church and with others becomes a deeply spiritual experience. It is an experience that can and should be renewed at regular intervals. In this sacrament you come into direct contact with Christ's mercy and his loving pardon. And here I appeal to priests to remember how important this ministry is for the sick and the aged' (John Paul II, 'Address to the Elderly, Perth, Australia, 30 November 1986', n. 6.).

4. Bringing the sick elderly person to the sacrament of the sick

Once the obstacle of self-closure has been overcome, and the portrayal of a God who punished through illness equally dealt with, the spiritual accompanying of a sick elderly person must lead to the request by him or her for the sacrament of the sick which 'benefits both soul and body and which the Church 'makes available' to the elderly not only in the case of grave illness but also when the weakness brought on by old age oppresses them.[67]

Sick elderly people 'feel deeply their need for the assistance of Christ and the Church' which is brought to them through the sacrament of the sick. In their situation of physical and spiritual suffering they are subjected not only to 'physical pain and weakness' but also to 'powerful anxieties and fears' and to 'temptations which they may never have faced before', the greatest temptation being despair, 'to the verge' of which they may be led. The anointing of the sick 'responds' to these 'precise needs' of a sick elderly person 'for it is a sacrament of faith, a sacrament for the whole person, body and soul'.[68]

5. The Special Vocation of Sick Elderly People

The spiritual accompanying of a sick elderly person is a process. It depends greatly on the development of illness in that person, on his or her level of consciousness or dulling of the senses, and on the steps that he or she is able to take in more serenely accepting his or her condition. It is also depends very much on his or her level of Christian formation and his or her previous life of faith.

When a sick elderly person is physically and spiritually able to understand this, the person providing the accompanying must make him or her understand the very positive role that his or her suffering, experienced accepting the will of God, can have for the Church and the salvation of souls. He or she must also make the person concerned aware that he or she is entrusted with a new vocation,[69] a new task: 'Men, as is known, appreciate wealth, power, physical strength, beauty and intellectual acumen. For God, instead, what is important above all else is the generous readiness with which one accepts one's own vocation and one seeks to perform one's task. A sick person who accepts the will of God and strives to implement it, in his eyes is worth more than a healthy person who seeks his or her success with the admiration and the envy of the world' (John Paul II, 'Address to the elderly and the sick, St. Stephen's Basilica, Budapest, 20 August 1991', n. 2.).

During this last stage of his or her life, a sick elderly person who has accepted his or her vocation knows by now that on his or her pathway towards holiness,[70] through suffering, he or she is not alone but, rather, from his or her bed of suffering, unknown and also at times abandoned, he or she brings a multitude of people towards eternal life.

6. Christian hope

The spiritual pathway of a sick elderly person can undergo ups and downs, moments of light and moments of darkness. But it must lead to Christian hope, beyond the temptation to despair. And it is because there is this temptation, this possibility of falling into darkness and self-closure, that one can talk about hope. It is this hope that allows sick elderly people to 'bear patiently heavy sufferings' and 'die full of trust', because, observed John Paul II, they should be certain that '*In te Domine speravi, non confundar in aeternum*': in you O Lord, I have hoped, I will not be lost eternally'.[71]

IV. SICK ELDERLY PEOPLE AT THE END OF THEIR LIVES AND ACCOMPANYING THEM UNTIL DEATH

The pastoral care of the Church for sick elderly people enters a special stage when these people, after a varyingly long pathway of illness and infirmity, reach the terminal stage of this illness and draw near to death. In these conditions these people are threatened by two opposing dangers: that of excessive treatment, which is defined as 'exaggerated treatment', and that of their elimination within the framework of euthanasia, assisted suicide or terminal palliative sedation.

By now it is the task of the Church to defend these vulnerable people who are without power and without a voice against these two opposing threats.

A. Against Technology that can Become Abuse

Exaggerated treatment was much spoken about during the 1960s when medical science acquired the modern techniques of resuscitation and had the tendency to advance in this area in an indiscriminate way. Today this happens less, in particular when the person treated in this way is elderly, of no economic and labour value, or without family or social supports. But it can still happen that a sick elderly person is artificially kept alive in response to a request that is advanced, for example, by his or her family.

The Church has never been in favour of this therapeutic excess which goes against the dignity of the human person and removes from this person that level of freedom which is needed to prepare for death. 'Today it is very important to protect, at the moment of death, both the dignity of the human person and the Christian concept of life, against a technological attitude that threatens to become an abuse' (*Iura et Bona*, IV, 5 May 1980).[72]

The Declaration *Iura et Bona* of the Congregation for the Doctrine of the Faith (1980) clearly invited patients to forgo abusive and useless forms of treatment when they are at the end of their lives: 'When inevitable death is imminent in spite of the means used, it is permitted in conscience to take the decision to refuse forms of treatment that would only secure a precarious and burdensome prolongation of life, so long as the normal care due to the sick person in similar cases is not interrupted' (*Iura et Bona*, IV, 5 May 1980).[73]

An assessment of this forgoing is based on the notion of the proportionate character of treatment. Only when 'the means of treatment available are objectively proportionate to the prospects for improvement' should they be continued.[74]

B. Against the Temptation of Euthanasia

The spiritual accompanying of sick elderly people at the end of their lives today often finds itself face to face with the increasingly widespread, albeit concealed, practices of euthanasia, assisted suicide or terminal sedation in the case of people who do not suffer.

The Church offers a dual response to these temptations: regarding the value of the life of an elderly sick person, to medical doctors, health-care workers or family relatives tempted to accelerate the natural process of death, or, even, to bring about the death of an elderly person whose life is seen as having little values; and regarding the duty of family relatives to accept and accompany in a physical and moral sense their elderly members who are at the end of their lives, or within the framework of palliative care.

1. Giving value to the life of an elderly person

Within the contemporary context of the 'culture of death', a sense of the sacred and intangible character of human life has been lost. 'This is not only a matter of individual selfishness but also of a social *conscience* which, *not believing in the inviolable value of life*, becomes its absolute and arbitrary master without appeal'.[75] This loss of a sense of the value of human life as such has led to the loss of respect for *every* human being. Human life is respected 'in general', but according to different degrees according to the value give to the kind of life considered. The value of the life of a sick elderly person who has been abandoned by his or her family, and who has few economic resources, can be seen as being located on the lowest level, that is to say that of being a disturbing 'burden' who occupies a hospital bed in an abusive way. One thus explains the ease with which society, in rich countries, has come to bestow on women almost a right to have an abortion, or on medical doctors, for example in Holland, the right to decide to engage in euthanasia or to facilitate assisted suicide. Also in countries where euthanasia continues to be prohibited in institutions, a form of concealed euthanasia on sick elderly people is practised under the legal cloak of a palliative 'sedation', even when these person are not suffering. The consequence of this is that a sick elderly person is in great danger as regards his or her life when events have led him or her to be taken to such institutions.

To those medical doctors or health-care workers who bestow upon themselves the right to eliminate in a physical sense those sick elderly people who are held to be 'useless' for whom they have responsibility, the Church can only state again her eternal principle: 'the inalienable principle of the sacredness and inviolability of life'[76]. 'Every human life has received its dignity from God that no one can violate. There must be no discrimination as regards the value of human life'.[77] 'Life' must be respected as an 'inalienable and sacred good'. 'An understanding of the sacred dignity of the human person leads to a giving of value to all the stages of life. This is a question of consistency and justice. Indeed, it is impossible truly to appreciate the life of an elderly person without truly appreciating the life of a child from the beginning of his or her conception'.[78] One cannot choose between different kinds of human life: all of them should be respected and protected. 'Every human life, even the most despised, marginalised and rejected, has an infinite value, because it is the object of the love of God. Thus the life of the unborn, of the sick and of the suffering, of the elderly, of the dying, as well of the young and of healthy people, is equally sacred and absolutely inviolable, from the moment of conception until its natural end' (John Paul II, 1989).[79]

2. Until death, accompanying life

The request for euthanasia or assisted suicide by a sick elderly person often expresses a state of deep affliction due to physical suffering that is not alleviated very much and to a situation of excessive malaise, to a situation of being abandoned by family relatives and to a situation of marginalisation and loneliness, as well as to all of these factors acting as a whole. Whereas physical pain can always be alleviated with the resources of modern pharmacology, the moral suffering that comes from a situation of being abandoned, of loneliness and of marginalisation raises more difficult problems that are not solved by medical science and to which the only valid answer comes not from technology but from the heart: 'The request which arises from the human heart in the supreme confrontation with suffering and death, especially when faced with the temptation to give up in utter desperation, is above all a request for companionship, sympathy and support in the time of trial. It is a plea for help to keep on hoping when all human hopes fail' (John Paul II, *Evangelium Vitae*, n. 67).

To such situations, the Church responds both with an appeal to the duties of the family, and with the development of high-quality palliative care where the accompanying of the sick person is of primary importance.

The family

The natural setting in which sick elderly people can best spend the last years of their lives is their families. A great part of the suffering and malaise of these people vanishes when they are with their families, their habitual environments, with the comfort of the presence of their children and grandchildren. As regards the duty to welcome its elderly parents of the family, there are certainly today some difficulties. But many families would like to have, and also could have, their elderly relatives with them in their homes until their deaths if they could benefit from forms of home care which cost less than the hospitalisation of people.[80]

Pope John Paul II laid emphasis on the role that families can have in accompanying their relatives until their deaths: 'Called to prophetic deeds in society, the Church defends life from its dawn to its conclusion in death. It is especially for this final stage, which often lasts for months and years and creates many serious problems, that I appeal today to the sensitivity of families, asking them to accompany their loved ones to the end of their earthly pilgrimage' (John Paul II, 'Address to the International Conference Organised by the Pontifical Council for Health Care Workers, 31 October 1998').

Pope Benedict XVI, when addressing the twenty-second international conference of the Pontifical Council for Health Care Workers on 17 November 2007 stressed this appeal of John Paul II to families, encouraging them to take care of their elderly relatives, to 'accept them and assume the duty with thankful affection, so that the aged sick can pass the final period of their life in their home and prepare for death in a warm family environment'.[81]

Even when hospitalisation of a sick elderly person requires his or her being cared for in a healthcare institution, families should be near to their elderly relatives, thereby keeping this vital link between the sick elderly person, his or her loved ones, and 'their own environment'.[82]

Accompanying Sick Elderly People who have been Admitted to Health-Care Institutions

When the family can no longer assure a welcome for a sick elderly relative, because of an absence or shortage of money, or because of the needs of treatment, pastoral care for sick elderly people is directed towards accompanying within the health-care institutions to which these people have been admitted. This becomes increasingly imperative when the prospect of a cure recedes[83] and there is a transfer to a palliative care unit.

Palliative care units have developed today throughout the world, in line with the common criteria of an absence of active treatment, the maintenance of ordinary treatment and the alleviation of pain. There can be no doubt about the value of these institutions.[84] However, it is also true that such units do not always respect what Saunders taught and practised, that is to say a real accompanying of the person until his or her death with a permanent presence at his or her side and care for all his or her needs, and in particular affective and spiritual needs. This is not only a matter of alleviating physical pain 'with the means that science and technology offer', but also of following people with 'skill and love, so that they do not feel that they are a useless burden and come, which is even worse, to wish for and ask for death. Our civilisation must assure elderly people a care that is rich in humanity and permeated by authentic values'.[85]

Within this context of palliative care what can really disappear is this 'concrete capacity to love' to which Benedict XVI referred and which the most sophisticated technology is unable to give and, even less, an artificial sleep induced by analgesics leading to the death of the patient 'Alongside the indispensable clinical treatment, however, it is always necessary to show a concrete capacity to love, because the sick need understanding, comfort and constant encouragement and accompaniment. The elderly in particular must be helped to travel in a mindful and human way on the last stretch of earthly existence in order to prepare serenely for death' (Benedict XVI, 'Address to the Participants at the Twenty-Second International Conference of the Pontifical council for Health Care workers, Sala Clementina, Sabato, 17 November 2007').[86]

V. THE CHURCH'S MESSAGE TO SICK ELDERLY PEOPLE

John Paul II in his numerous addresses to elderly and sick people was always keen to give to these people not only a message of encouragement and support in their affliction but also a strong exhortation not to give way to resignation and to live to the full the last stages of their lives in the spirit of a specific mission.

A. You Should not Stop

The first words of encouragement that John Paul II generally addressed to these people were not to become resigned, not to give up, and not to say 'enough':

'Nobody has the right to say enough, You should not stop, nor should you see yourselves as being in decline' (John Paul II, 'Address to Groups of Elderly People of Italian Diocese', 23 March 1984', n. 3).[87]

In the observations that the Pontifical Council for the Laity made indirectly to sick elderly people, within the framework of pastoral activity suited to their needs, a primary place was given to not taking into account the idea that they were 'useless' and a 'burden' that they may receive from the outside world, but to 'grasp', in an opposite fashion, the sense of their age, 'to appreciate its resources, and to overcome the temptation to reject it, and so succumb to self-isolation, resignation and a feeling of uselessness and despair' (The Pontifical Council for the Laity, *The Dignity of the Older Person,* III, 1998).[88]

B. You Still Have a Mission to Carry out, a Contribution to Make

The profound thought of John Paul II on suffering led him to the strong belief that sick elderly people, despite their apparent uselessness and their physical distancing from all activity of the Church, not only have a right to a specific place within the Church but also have a specific vocation, a specific task, to perform in the daily experience of their physical, moral and spiritual suffering. It was therefore important for Pope John Paul II to make these people understand their own evangelising mission, their mission of witness and of active cooperation in the work of redemption. This was the message full of energy and hope that John Paul II transmitted to sick elderly people with the following strong words: 'You still have a mission to fulfil, a contribution to make' (John Paul II, *Christifideles laici*, 30 December 1988, n. 48).

C. Society Needs You

The third message that John Paul II often addressed to sick elderly people was that, very far from being useless, they are important for the world and for the Church. This was an authentic leitmotiv that the Pope habitually emphasised for them: 'Society needs you, the Church needs you' (John Paul II, 'Address to Young People, Elderly People and the Handicapped, Vancouver Stadium, Tuesday, 18 September, 1984', n. 3).

It was in these terms, full of force and energy, that John Paul II spoke to a group of elderly people in Vienna, Austria, in 1983: 'And now I want to look above all at you, bent with the weight of years and suffering from the pains and the limitations of old age…We need your experience of faith and your example. You must not separate yourselves. You are a part of us!' (John Paul II, 'Address to the Elderly of the House of Mercy, Vienna, Sunday, 11 September 1983', n. 2).

These were not empty words, mere courtesies: they really corresponded to what the Pope expected of these elderly people: he expected from them their ordinary lives as elderly people, suffering but believers and praying for the Church and for the world; he expected from them above all else 'their life of prayer – at times accompanied by suffering' to bring 'the redeeming love of Christ to the world' (John Paul II, 'Address to Elderly People, Perth, Australia, 30 November 1986', n. 7).

In 1988 in Salzburg cathedral John Paul II ended his message to the elderly and the sick in the cathedral in the following way: 'I want to repeat to you once again that the Church needs you. In you we recognise the presence of Christ who continues to live amongst us marked by the cross and by suffering. And if you accept the sufferings that are inflicted on you, your prayer and your sacrifice to God will have an incredible strength. Do not stop, therefore, praying! Pray and offer up yourselves for the Church, for the salvation of men and also pray for my apostolic mission' (John Paul II, 'Homily to the Elderly and the Sick, Salzburg Cathedral, 26 June 1988', n. 7).

Prayer and sacrifice: this was the programme of Pope John Paul II for the sick elderly people who listened to him. This was certainly not a gentle message; but it was the message that touched these people because it came from his own experience, it corresponded totally to their condition of being suffering people: 'Because of the special conditions of age in which you find yourselves, there is no absence of opportunities to suffer or time to pray. To be saved the world needs prayer and suffering. You can help it' (John Paul II, 'Address to Groups of Elderly People of Italian Dioceses, 23 March 1984').[89]

CONCLUSION: PASTORAL CARE FOR SICK ELDERLY PEOPLE

The teaching of the papal Magisterium of recent times as regards sick elderly people has, therefore, been rich and abundant. Many concrete points can be gathered from this teaching as guidance for the specific pastoral care of the Church in this field. I will address in this conclusion two of these: the need for a specific spiritual accompanying of these people and the openness of this accompanying to a death lived serenely, in faith, with a time of hope.

A. Sick Elderly People Need to be Supported in their Trial by an Accompanying of Love and Solidarity

The situation of suffering and of frequent marginalisation of sick elderly people easily leads them to despair and to shut themselves up inside it if they do not find at their side a caring and faithful presence, a source of gratuitous and generous love, of *solidarity* and of support in affliction.[90]

In a world of the technological and of efficiency, in the healthcare field as well, their situation is a call for another world, that of gratuitous and generous love that 'stirs in the hearts of those who have compassion'. However, this accompanying has its requirements if it is to meet the 'request which arises from the human heart in the supreme confrontation with suffering' (John Paul II, *Evangelium Vitae* n. 67). It should not be an anonymous accompanying made up of 'specialists', as can be done for sick adults. Here the heart of a sick elderly person asks to for more: 'the affectionate presence of those he loves and his friends'.[91] Thus, in the view of John Paul II, 'the true objective of "pastoral" care for the aged, especially when they are sick, and more so if gravely sick' is having the elderly person 'surrounded by brethren in the faith who are ready to listen and to share his sentiments' (Benedict XVI, 2007).[92]

B. Accompanying to Death as a Time of Hope

The accompanying of a sick elderly person is naturally open to and directed towards death, about which a sick elderly person never stops thinking, but a death that is 'reinserted in human life' as the 'last act of earthly life', which can therefore be welcomed and taken on 'in dignity and serenity'.[93] This is possible if an elderly person is led by the 'affectionate presence' of his 'brethren in faith' to move from self-contempt and the dark abyss of despair to trust in the God of love and the light of hope. It is in such conditions of suffering taken on with a trusting self-abandonment to the hands of God that death ' no longer a condemnation, no longer a meaningless epilogue of life signifying nothing – is revealed as a time of hope: the true and certain hope of coming face to face with the Lord' (the Pontifical Council for the Laity, 'The Dignity of the Older Person, III, 1998).[94]

C. Death: a Sister who Leads us to the Arms of the Father

The last step on this journey of faith to which a sick elderly person is invited, from the depths of his or her suffering, is, for that person, to be able to go from hope experienced as light in the darkness to the hope illumined by Christ, 'full of immortality'. This was the mystical vision of St. Francis of Assisi. It was also the mystical vision of John Paul II when he declared, taking up a phrase of St. Francis: 'In Christ, death – tragic and disconcerting as it is – is redeemed and transformed; it is even revealed as a "sister" who leads us to the arms of our Father' (John Paul II, 'Letter to the Elderly, 1999', n. 15).[95]

Notes

[1] 'The Church's attention and commitment to older people are nothing new. She has directed her mission and pastoral care to older people in the most varied circumstances over the centuries. Christian "*caritas*" has embraced their needs; it has given rise to the most varied forms of apostolate at the service of older people, especially thanks to the initiative and concern of religious congregations and lay associations': *La dignità dell'anziano e la sua missione nella Chiesa e nel mondo* ('The Dignity of Older People and their Mission in the Church and the World') n. 3, Pontificio Consiglio per i Laici, 'Introduzione', 1 ottobbe 1998, Enchiridion Vaticanum 17, 1988, Edizioni Dehoniane, Bologna, 2000, pp. 1146-1173, n. 1476.

[2] 'As regards elderly people who need special care, the Catholic Church, through the organisation of 15,448 homes for elderly people, chronically ill people and the disabled throughout the world, sees the increase in the number of elderly people as a 'blessing' rather than as a burden for society': speech of Archbishop Silvano Tomasi, Permanent Observer of the Holy See at the Office of the United Nations and Specialised Institutions in Geneva, on 'The Right of Elderly People to Health', at the seventeenth session of the Council of Human Rights in Geneva, Friday, 16 September 2011.

[3] 'The fundamental aspects of the third and fourth ages naturally relate to the weakening of physical strength, a lesser vivacity of the spiritual faculties, a steady detachment from activities to which one was attached, sickness and being an invalid, the prospect of separation as regards the affections because of a departure for the world beyond: Giovanni Paolo II, 'Messaggio ai partecipanti all'assemblea mondiale sui problemi dell'invecchiamento della popolazione', 22 July 1982, *Insegnamenti di Giovanni Paolo II*, Libreria Editrice Vaticana 1982, 1982, V, 3 (luglio-dicembre, pp. 123-232, see p.126).

[4] 'In Christ, death — tragic and disconcerting as it is — is redeemed and transformed; it is even revealed as a "sister" who leads us to the arms of our Father': Giovanni Paolo II, *Lettera agli anziani* ('Letter to the Elderly') 10, *Enchiridion Vaticanum* 18 1989, Edizioni Dehoniane, Bologna, 2002, pp. 994-1035, see n. 1685, p. 1033.

[5] 'In the face of the so-called culture of death, the family is the heart of the culture of life': John Paul II, encyclical letter *Centesimus Annus* on the centenary of *Rerum Novarum*, 1 May 1991, n. 39 (*Acta Apostolica Sedis*, vol. LXXXIII, 1991, pp.793-867) .

'Over recent days you have asked yourselves from which foundations one must start to promote or reactivate a culture of life and with which contents to propose it to a society marked – as I observed in the encyclical *Evangelium Vitae* – by an increasingly widespread and alarming culture of death': John Paul II to the members of the Pontifical Academy for Life, 3 March 2001, *Acta Apostolica Sedis*, vol XCIII, 2001, pp. 445-448, see p. 445.

'Unfortunately, it seems that the "culture of death" is advancing on many fronts and is also threatening the season of old-age': Benedict XVI, 'Address to those Taking Part in the Plenary Assembly of the Pontifical Council for the Family, 5 April 2008'.

[6] *La dignità dell'anziano e la sua missione nella Chiesa e nel mondo*,Introduzione, Pontificium Consilium Pro Laicis, 1° Ottobre 1998, *Enchiridion Vaticanum* 17, 1988, Edizioni Dehoniane, Bologna, 2000, pp. 1146-1173, n. 1471.

[7] 'This kind of "silent revolution" goes far beyond the demographic data: it poses social, economic, cultural, psychological and spiritual problems of a magnitude which has for some time been a matter of concern to the international Community: (The Pontifical Council for the Laity, 'The Dignity of Older People and their Mission in the Church and the World', 1998), *La dignità dell'anziano e la sua missione nella Chiesa e nel mondo*, 'Introduzionep, Pontificium Consilium Pro Laicis, 1 ottobre 1998, *Enchiridion Vaticanum* 17, 1988, Edizioni Dehoniane, Bologna, 2000, pp.1146-1173, n. 1472.

[8] 'One should emphasise again, it is the whole of society that deprives itself of elements that enrich and regulate when it ventures to recognise as valuable for its development only its young members and adults in the full possession of their strength, and to relegate all the others to the category of the unproductive': John Paul II, 'Message to the World assembly on the Problems of Ageing', 26 July 1982, *Insegnamenti di Giovanni Paolo II 1982*, Libreria Editrice Vaticana, 1982, V, 3, luglio-dicembre, pp.123-131, see p. 127.

[9] 'People today live longer and enjoy better health than in the past. They are also able to cultivate interests made possible by higher levels of education. No longer is old age synonymous with dependence on others or a diminished quality of life. But all this seems not enough to dislodge a negative image of old age or encourage a positive acceptance of a period of life in which many of our contemporaries see nothing but an unavoidable and burdensome decline': *La dignità dell'anziano e la sua missione nella Chiesa e nel mondo*, n. 1, Pontificium Consilium Pro Laicis, 1 ottobre 1998, *Enchiridion Vaticanum* 17, 1988, Edizioni Dehoniane, Bologna, 2000, pp. 1146-1173, n. 1479.

[10] 'In the past, great respect was shown to the elderly. "Great was once the reverence given to a hoary head", says Ovid, the Latin poet (*Magna fuit quondam capitis reverentia cani*", Fasti, lib.V, v. 57.). Centuries earlier, the Greek poet Phocylides had admonished: "Respect grey hair: give to the elderly sage the same signs of respect that you give your own father" (Sententiae, XLII): Giovanni Paolo II, *Lettera agli anziani*, n. 9, *Enchiridion Vaticanum*, 18, 1999, Edizioni Dehoniane, Bologna, 2002, pp. 995-1035, n. 1662, p. 1013.

[11] 'The perception of old age as a period of decline, in which human and social inadequacy is taken for granted, is in fact very widespread today. But this is a stereotype. It does not take account of a condition that is in practice far more diversified, because older people are not a homogeneous human group and old age is experienced in very different ways': *La dignità dell'anziano e la sua missione nella Chiesa e nel mondo*, n. 1, Pontificium Consilium Pro Laicis,

1 ottobre 1998, *Enchiridion Vaticanum* 17, 1988, Edizioni Dehoniane, Bologna, 2000, pp.1146-1173, n. 1480.

[12] Giovanni Paolo II, *Lettera agli anziani*, n. 9, *Enchiridion Vaticanum*, 18, 1999, Edizioni Dehoniane, Bologna, 2002, pp. 995-1035, n. 1662, p. 1013.

[13] Encyclical letter *Evangeliun Vitae* of the Supreme Pontiff John Paul II to the bishops, priests and deacons, men and women religious, lay faithful and all people of good will on the value and inviolability of human life, 25 March 1995, n. 64.

[14] Encyclical letter *Evangeliun Vitae* of the Supreme Pontiff John Paul II to the bishops, priests and deacons, men and women religious, lay faithful and all people of good will on the value and inviolability of human life, 25 March 1995, n. 64.

[15] *La dignità dell'anziano e la sua missione nella Chiesa e nel mondo*, n. 3, Pontificio Consiglio per i Laici, 1 ottobre 1998, *Enchiridion Vaticanum* 17, 1988, Edizioni Dehoniane, Bologna, 2000, pp.1146-1173, nn. 1498-1499, n. 1498, p. 1157.

[16] *La dignità dell'anziano e la sua missione nella Chiesa e nel mondo*, n. 3, Pontificio Consiglio per i Laici, 1 ottobre 1998, *Enchiridion Vaticanum* 17, 1988, Edizioni Dehoniane, Bologna, 2000, pp.1146-1173, nn. 1498-1499, n. 1498, p. 1157.

[17] Elderly people… reach the point of despising themselves when that of primary importance is the performance of citizens… Such a climate…necessarily generates a folding in one oneself, painful feelings of uselessness and in the end despair': Giovanni Paolo II, *Messaggio all'assemblea mondiale sui problemi dell'invecchiamento della popolazione*, I, 26 luglio1982, *Insegnamenti di Giovanni Paolo II 1982*, Libreria Editrice Vaticana, 1982, V, 3, luglio-dicembre, pp. 123-131, see p. 127.

[18] *La dignità dell'anziano e la sua missione nella Chiesa e nel mondo*, n. 1, Pontificium Consilium Pro Laicis, 1. ottobre 1998, *Enchiridion Vaticanum* 17, 1988, Edizioni Dehoniane, Bologna, 2000, pp. 1146-1173, n. 1500 p. 1158.

[19] Benedict XVI, Address during the Visit to the 'Viva gli Anziani' Home managed by the Community of San Egidio, Rome, Monday, 12 November 2012'..

[20] Giovanni Paolo II, *Lettera ai partecipanti alla II assemblea mondiale sull'invecchiamento*, 3 aprile 2002, *Enchiridion Vaticanum*, 21, 2002, Edizioni Dehoninae, Bologna, 2005, pp. 209-215, see p. 211, n. 258.

[21] 'Even its setting has changed: it is no longer at home that most people die: older people in particular, increasingly separated from their own human community, ever more frequently die in hospitals or in institutions. Mourning rites and many forms of piety towards the dead are becoming increasingly rare, especially in the cities. Numbed by the daily images of death presented by the media, people today do everything in their power to avoid coming to terms with a reality which causes them only distress, anxiety and fear. It is inevitable therefore that, as their own death approaches, they are often alone': *La dignità dell'anziano e la sua missione nella Chiesa e nel mondo*, n. 3, Pontificio Consiglio per i Laici, 1 ottobre 1998, *Enchiridion Vaticanum* 17, 1988, Edizioni Dehoniane, Bologna, 2000, pp. 1146-1173, nn 1498-1499, see p.1155, n. 1495.

[22] 'By using highly sophisticated systems and equipment, science and medical practice today are able not only to attend to cases formerly considered untreatable and to reduce or eliminate pain, but also to sustain and prolong life even in situations of extreme frailty, to resuscitate artificially patients whose basic biological functions have undergone sudden collapse, and to use special procedures to make organs available for transplanting': John Paul II, *Evangelium Vitae*, n. 64.

[23] A sick elderly person at the end of their life can today be subjected more or less voluntarily to the threat of exaggerated treatment, 'in other words, medical procedures which no longer correspond to the real situation of the patient, either because they are by now disproportionate to any expected results or because they impose an excessive burden on the patient and his family' (John Paul II, *Evangelium Vitae* n. 65.).

[24] Benedetto XVI, Discorso ai partecipanti alla XXII conferenza internazionale del Pontificio Consiglio per gli operatori sanitari, Sala Clementina, Sabato, 17 novembre 2007*, Acta Apostolica Sedis*, 5 Decembris 2008, anno C, n. 12, pp. 840-842.

[25] 'Address of the Holy Father Francis to those taking part in the meeting organised by the International Federation of Associations of Catholic Doctors, Sala Clementina, 20 September 2013'.

[26] 'it can then happen that those who are advanced in years find themselves in a situation of inner malaise, of increasing suffering, accompanied by loneliness and discomfort. It is not always easy to accept events in a serene spirit and one remains in silence in front of the will of the Lord! It is difficult to penetrate it': John Paul II, 'Address to the Elderly Members of the Brancaccio Rest Home, 27 April 1991'.

[27] Pio XII, *Discorso intorno tre quesiti religiosi e morali concernenti l'analgesia*, conclusione, 24 febbraio 1957, *Acta Apostolica Sedis*, 1957, anno XXXXIX, series II; vol. XXIV, pp. 129-147, see p. 147.

[28] Pio XII, *Discorso intorno tre quesiti religiosi e morali concernenti l'analgesia*, III, 24 febbraio 1957, *Acta Apostolica Sedis*, 1957, anno XXXXIX, series II; vol. XXIV, pp. 129-147, see p.146.

[29] Pio XII, *Discorso intorno tre quesiti religiosi e morali concernenti l'analgesia*, I, 24 febbraio 1957, *Acta Apostolica Sedis*, 1957, anno XXXXIX, series II; vol. XXIV, pp. 129-147, see p.145.

[30] Pio XII, *Discorso intorno tre quesiti religiosi e morali concernenti l'analgesia*, I, 24 febbraio 1957, *Acta Apostolica Sedis*, 1957, anno XXXXIX, series II; vol. XXIV, pp. 129-147, see p.145.

[31] ““‘it is not right to deprive the dying person of consciousness without a serious reason”: as they approach death people ought to be able to satisfy their moral and family duties, and above all they ought to be able to prepare in a fully conscious way for their definitive meeting with God': John Paul II, *Evangelium vitae*, n. 65.

[32] 'human and Christian prudence suggest for the majority of sick people the use of medicines capable of alleviating or suppressing pain, even though these may cause as a secondary effect semi-consciousness and reduced lucidity. As for those who are not in a state to express themselves, one can reasonably presume that they wish to take these painkillers, and have them administered according to the doctor's advice': Sacra Congregazione per la Dottrina della Fede, *Dichiarazione sull'eutanasia*, III, 5 maggio 1980, *Acta Apostolica Sedis*, 1980, vol. LXXII, pp. 542-552, see pp. 547-548.

[33] 'The mystery of human suffering overwhelms the sick person and poses disturbing new questions: Why is God allowing me to suffer? What purpose does it serve? How can God who is good permit something which is so evil? There are no easy answers to these questions asked by the burdened mind and heart. Certainly, no satisfying answer can be found without the light of faith': John Paul II, 'Address to the Sick, the Elderly and the Handicapped', Wellington Show and Sport Centre, Wellington, New Zealand, 22 November 1986', n. 2.

[34] 'Prostration and forced inactivity can force a sick person to fold in on himself. We should not therefore be surprised if illness can draw a person nearer to God or lead to hopelessness: John Paul II, 'Meeting with the Sick and the Elderly, Callao, Peru, 4 February 1985'.

[35] 'There are those who in pain fold in on themselves, becoming insensitive to others; there are those who in bitterness lose hope. Suffering, without the intelligent and courageous cooperation of the person, does not automatically save one from shallowness and selfishness': John Paul II, 'Address to the Elderly and the Sick, St, Stephen's Basilica, Budapest, 20 August 1991'.

[36] 'In your suffering you experience in a practical way the finiteness and the limited character of the creature. Specifically for this reason, however, suffering can become for us the most privileged moment of opening up to others and to God. A life that is flat and without questions easily leads us to shallowness and to making us feel sated and self-sufficient. Instead, when suffering provokes us with its inevitable questions, it is there that we feel nostalgia strongly. And, renewed, we search for others and in our intimate selves for God: John Paul II, 'Homily to the Sick and the Elderly, Salzburg Cathedral, 26 June 1988', n. 2.

[37] 'Blessed are those who know how to recognise the hand of God in tribulation. God cannot be beaten as regards generosity, At times it is precisely through suffering that He knocks on the door of the heart, in the wish to establish a special relationship of friendship which, if corresponded, can acquire the warmth and intimacy of a fine experience: 'I will dine with him and he with me (Ap 3:20)'': John Paul II, 'Address to the Elderly and the Sick, St. Stephen's Basilica, Budapest, 20 August 1992', n. 2.

[38] 'It is true, unfortunately, that is this ascension towards holiness through suffering one can also fail and stop. One has to fight. But in this undertaking one is never alone, not even for an second. The Father is at our side and He holds our hand and effuses generously into us His Holy Spirit to make us grow in the awareness that we are His children. Specifically through the experience of our frailty we are led to discover the loving presence of God and to cry out our pain to He who alone can give us true relief. Suffering thus becomes a school of felt, insistent and trusting prayer: John Paul II, 'Address to the Elderly and the Sick, St. Stephen's Basilica, Budapest, 20 August 1992', n. 2.

[39] John Paul II, 'Meeting with the Sick and the Elderly, Callao, Peru, 4 February 1985', n. 3.

[40] *Ibidem.*

[41] 'The fundamental aspects of the third and fourth ages…can be transformed by philosophical beliefs and above all by the certainties of faith for those who have the joy to believe. For these last, indeed, the last stage of life on earth can be experienced as a mysterious accompanying of Christ the Redeemer, who followed his painful pathway of the cross before the radiant dawn of Easter': John Paul II, 'Message to the Participants at the World Assembly on the Problems of the Ageing of the Population', 22 July 1982.

[42] 'We note, with consolation, Jesus' promise that our souls will find rest - not our bodies but our souls. Jesus does not promise to remove all physical suffering from our

lives during our earthly pilgrimage, but he does promise to refresh our spirits, to lift up our hearts, to give rest to our souls' John Paul II, 'Address to Sick and Elderly People at the Martyrs' Shrine of Huronia, Saturday 15 September 1984', n. 4.

[43] 'You, dear brothers and sisters, well know by experience that technical services and health care are not sufficient even when they are engaged in with diligent professionalism. A sick person is a human person and as such needs to feel the affectionate presence of those whom he or she loves and his or her friends. This presence is a spiritual medicine that restores love to life and persuades people to fight for it with an inner strength that by no means rarely contributes in a decisive way to healing': John Paul II, 'Meeting with the Sick and the Elderly, Callao, Peru, 4 February 1985', n. 2.

[44] Pio XII, *Tre quesiti religiosi e morali concernenti l'analgesia*, *Allocutio ad partecipantes XI Congressum Societatis Italicae de anaesthesiologia*, I, 24 febbraio 1957, *Acta Apostolica Sedis*, 1957, anno XXXXIX, series II, vol. XXIX, pp. 129-147, see p.135.

[45] 'the life and the passion of the Lord, the pains that so many great men have borne and even sought as a result of which they became giants and even arrived at the summits of Christian heroism, the daily examples of willing acceptance of the cross that are present, all of this reveals the meaning of suffering, of the patient acceptance of pain in the contemporary economy of salvation, during the time of this life on earth': Piu XII, *Allocutivo ad partecipante IX Congressum Societatis Italicae de anaesthesiologia*, I, 24 febbraio 1957, *Acta Apostolica Sedis*, 1957, anno XXXXIX, series II, vol XXIX, pp. 129-147, see p.135.

[46] Piu XII, *Allocutivo ad partecipante IX Congressum Societatis Italicae de anaesthesiologia*, I, 24 febbraio 1957, *Acta Apostolica Sedis*, 1957, anno XXXXIX, series II, vol. XXIX, pp. 129-147, see p.135.

[47] 'And what should be said about your suffering?...his Passion and therefore the Redemption must be completed (Col 1:24) by our suffering, therefore you are not useless, beloved sons and daughters. Through your supernatural pain that is offered up, you can conserve so many forms of innocence, call back to the path of righteousness so many of those who have gone off the right path, illuminate so many doubting people, and restore serenity to so many in tribulation': Pius XII, Consociationi Italiae "Centro di volontari della Sofferenza" *aegrotisque eidem adscriptis, Romae coadunatis*, 7 ottobre 1957, *Acta Apostolica Sedis*, 1957, anno XXXXIX, series II, vol. XXIV, pp. 954-958, see p. 958.

[48] 'According to Christian teaching, however, suffering, especially suffering during the last moments of life, has a special place in God's saving plan; it is in fact a sharing in Christ's passion and a union with the redeeming sacrifice which He offered in obedience to the Father's will': Sacra Congregazione per la Dottrina della Fede, Dichiarazione sull'eutanasia *Iura et bona*, 5 maggio 1980, *Acta Apostolica Sedis*, 1980, vol. LXXII, pp. 542-552.

[49] Giovanni Paolo II, Lettera apostolica *Salvifici Doloris*, ai vescovi, ai sacerdoti, alle famiglie religiose ed ai fedeli della Chiesa Cattolica sul senso cristiano della sofferenza umana, 11 febbraio 1984, *Acta Apostolica Sedis*, 1984, vol. LXXVI, n. 2, 1 Martii 1084, pp. 201-250, see n. 24, pp. 232-233.

[50] Giovanni Paolo II, Lettera apostolica *Salvifici Doloris*, ai vescovi, ai sacerdoti, alle famiglie religiose ed ai fedeli della Chiesa Cattolica sul senso cristiano della sofferenza umana, 11 febbraio 1984, *Acta Apostolica Sedis*, 1984, vol. .LXXVI, n. 2, 1 Martii 1084, pp. 201-250, see n. 24, p.233.

[51] Giovanni Paolo II, Lettera apostolica *Salvifici Doloris*, ai vescovi, ai sacerdoti, alle famiglie religiose ed ai fedeli della Chiesa Cattolica sul senso cristiano della sofferenza umana, 11 febbraio 1984, *Acta Apostolica Sedis*, 1984, vol. LXXVI, n. 2, 1 Martii 1084, pp. 201-250, see n. 19, p. 226.

[52] Giovanni Paolo II, Lettera apostolica *Salvifici Doloris*, ai vescovi, ai sacerdoti, alle famiglie religiose ed ai fedeli della Chiesa Cattolica sul senso cristiano della sofferenza umana, 11 febbraio 1984, *Acta Apostolica Sedis*, 1984, vol. LXXVI, n. 2, 1 Martii 1084, pp. 201-250, see n. 25, p. 236.

[53] 'Down through the centuries and generations it has been seen that *in suffering there is concealed* a particular *power that draws a person interiorly close to Christ,* a special grace': Giovanni Paolo II, Lettera apostolica *Salvifici Doloris*, ai vescovi, ai sacerdoti, alle famiglie religiose ed ai fedeli della Chiesa Cattolica sul senso cristiano della sofferenza umana, 11 febbraio 1984, *Acta Apostolica Sedis*, 1984, vol LXXVI, n. 2, 1 Martii 1084, pp. 201-250, see n. 26, p. 238.

[54] Giovanni Paolo II, *Lettera agli anziani*, n. 10, *Enchiridion Vaticanum*, 18, 1999, Edizioni Dehoniane, Bologna, 2002, pp. 995-1035, n. 1674, p. 1025.

[55] 'You, dearest brothers and sisters, are participants in his work of redemption and, humanly speaking, your lives could appear to be failures, but from the point of view of Christ, of the Gospel, of Providence, your lives are very fruitful and contribute to the spiritual good of humanity and of the Church': John Paul II, 'Address on the Occasion of the Feast of the Dedication of St. John's Basilica in the Lateran. Sunday, 9 November 1986'.

[56] John Paul II, 'Meeting with the Eldfery and theSsick in the Catholic Cathedral of St. Henrik, 6 June 1989'.

[57] 'First of all. the very weakness which you feel, and particularly the love and faith with which you accept that weakness, remind the world of the higher values in life, of the things that really matter… Through the pain and the disabilities that restrict your life, you can proclaim the Gospel in a very powerful way. Your joy and patience are themselves silent witnesses to God's liberating power at work in your lives: John Paul II, 'Address to the Sick, the Elderly and the Handicapped at the Wellington Show and Sport Centre, Wellington, New Zealand, 22 November 1986', n. 6.

[58] 'in a few words, many people are led to the faith by those who every day draw from their faith the strength to make their illness a teaching chair of a witness that is that much more convincing the more silent it is': John Paul II, 'Address to the Sick and the Elderly, St. Stephen's Basilica, Budapest, 20 August 1991', n. 3.

[59] 'The Church well knows that by no means few people draw near to God in particular during the so-called 'third age', and that specifically during that period they can be helped to rejuvenate their spirits on the ways of reflection and sacramental life. The experience accumulated down the years leads an elderly person to understand the limits of the things of this world and to feel a deeper need for the presence of God in earthly life. The disappointments experienced in some circumstances have taught him or her to place his or her trust in God': Giovanni Paolo II, Udienza Generale, 7 settembre 1994, *L'Attività della Santa Sede 1994*, Libreria Editrice Vaticana, 1995, pp. 589-593.

[60] 'Religious practice occupies a key place in the life of older persons. The third age seems particularly conducive to transcendental values. Confirmation of this is given, among other things, by the frequent and numerous participation of older people in liturgical celebrations, by the unexpected return of many of them to the Church after long years of absence, and by the important role played by prayer in their lives. Prayer represents in fact an inestimable contribution to the spiritual resources of devotion and sacrifice, from which the Church copiously draws and which need to be fostered both within Christian communities and within families' 'La dignità dell'anziano e la sua missione nella Chiesa e nel mondo', n. 4, Pontificium Consilium Pro Laicis, 1 ottobre 1998, *Enchiridion Vaticanum* 17, 1988, Edizioni Dehoniane, Bologna, 2000, pp. 1146-1173, see n. 1511, p. 1161.

[61] 'Human suffering, however, tempts us to doubt the words of Jesus that the Kingdom of God is near. When pain dulls the mind and weighs down body and soul, God can seem far away; life can become a heavy burden': John Paul II, 'Address to the Sick, the Elderly and the Handicapped at the Wellington Show and Sports Centre, Wellington, New Zealand, 23 November 1986', n. 3.

[62] *La dignità dell'anziano e la sua missione nella Chiesa e nel mondo*, n. 4, Pontificium Consilium Pro Laicis, 1 ottobre 1998, *Enchiridion Vaticanum* 17, 1988, Edizioni Dehoniane, Bologna, 2000, pp. 1146-1173, see n. 1513 p. 1161.

[63] 'Younger people cannot fully understand the way in which the elderly sometimes return to the distant past, but such reflection has its place. And when it is done in prayer it can be a source of healing. I am speaking of the important spiritual healing that restores inner freedom to the elderly. This kind of healing is gained through an awareness and appreciation of the ways in which God works through human weakness as well as through human virtue': John Paul II, 'Address to the Elderly, Perth, Australia, 30 November, 30 November 1986', nn. 5-6.

[64] 'The ecclesial community has the responsibility to purify this fatalism by helping to develop the religious faith of older people and by restoring a horizon of hope to it. In this task, catechesis has a role of primary importance to play. It is the job of catechesis to purge faith of fear, to overcome the image of a wrathful God, and to lead the older person to discover the God of love': *La dignità dell'anziano e la sua missione nella Chiesa e nel mondo*, n°4, Pontificium Consilium Pro Laicis, 1 ottobre 1998, *Enchiridion Vaticanum* 17, 1988, Edizioni Dehoniane, Bologna, 2000, pp. 1146-1173, see n. 1513 p. 1161.

[65] John Paul II, 'Address to Elderly People, Perth, Australia, 30 November 1986', n. 5.

[66] 'Even the memory of our sins does not discourage us any longer, because we realize that God's mercy is greater than our sins and that God's pardon is a proof of his faithful love for us…The promise of resurrection enables the aged to see all of life in a totally different way': John Paul II, 'Address to Elderly people, Perth, Australia, 30 November 1986', n. 6.

[67] 'Then too there is the Sacrament of the Sick, which benefits both soul and body. The Church asks that through the anointing with oil and the prayer of faith our sins be forgiven, that the remnants of sin be taken away and that the increase of grace be accompanied by an improvement of health, if God so wishes if for our good. I hope that you will approach this sacrament with confidence. The Church makes this sacrament available to the elderly not only when they are gravely ill but also when the weakness of ageing weighs them

down. When I was in hospital five years ago I myself derived much comfort from it.': John Paul II, 'Address to Elderly People, Perth, Australia, 30 November 1986', n. 6.

[68] John Paul II, 'Address to the Sick, the Elderly and the Handicapped' at the Wellington Show and Sports Centre, Wellington, New Zealand, 23 November 1986', n. 5.

[69] 'The believer must reflect unceasingly on the value of participation in the sufferings of Christ in order to live and make live in a more intense way *the special vocation* inherent in the condition of old age or illness': John Paul II, 'Address to the Elderly and the Sick, St. Stephen's Basilica, Budapest, 20 August 1991', n. 2.

[70] 'The pastoral task of evangelizing or re-evangelizing older members of the community must aim at fostering the spirituality that is peculiar to this age of life: i.e. a spirituality based on the continual rebirth that Jesus himself recommended to the elderly Nicodemus…Christ's call to holiness is addressed to all his disciples, in every phase of human life…In spite of the passing of years, which risks dampening enthusiasm and draining away energy, older people must therefore feel themselves more than ever called to persevere in the search for Christian holiness': *La dignità dell'anziano e la sua missione nella Chiesa e nel mondo*, n°4, Pontificium Consilium Pro Laicis, 1 ottobre 1998, *Enchiridion Vaticanum* 17, 1988, Edizioni Dehoniane, Bologna, 2000, pp. 1146-1173, see n. 1518 p. 1162.

[71] John Paul II, 'Address to the Elderly and the Sick, Munster Cathedral, Friday 1 May 1987'.

[72] Sacra Congregazione per la Dottrina della Fede, *Dichiarazione sull'eutanasia*, n. IV, *Acta Apostolica Sedis*, 1980, vol. LXXII, pp. 542-552, see p. 549.

[73] Sacra Congregazione per la Dottrina della Fede, *Dichiarazione sull'eutanasia*, n. IV, *Acta Apostolica Sedis*, 1980, vol. LXXII, pp. 542-552, see p.551.

[74] 'Certainly there is a moral obligation to care for oneself and to allow oneself to be cared for, but this duty must take account of concrete circumstances. It needs to be determined whether the means of treatment available are objectively proportionate to the prospects for improvement. To forego extraordinary or disproportionate means is not the equivalent of suicide or euthanasia; it rather expresses acceptance of the human condition in the face of death: John Paul II, *Evangelium vitae*, n. 65.

[75] *Ai partecipanti al convegno sulla vita promosso dalla CEI*, Roma, 16 aprile 1989, in *Insegnamenti* xi,1 (1989), 836.

[76] Illness and suffering are privileged means for reminding us of the inalienable principle of the sacredness and inviolability of life...Man cannot arbitrarily choose to live or die, or decide on the life or death of others: that is a choice which only he in whom "we live, and move and exist" can make': *La dignità dell'anziano e la sua missione nella Chiesa e nel mondo*, III, Pontificium Consilium Pro Laicis, 1 ottobre 1998, *Enchiridion Vaticanum* 17, 1988, Edizioni Dehoniane, Bologna, 2000, pp. 1146-1173, see n. 1535 p. 1167.

[77] 'Specifically when amongst you, I want to address the whole of society: there must be no discrimination as regards the value of human life. This discrimination gave rise a few decades ago to one of the worst barbarities. There are no lives that have a value and others that do not. Every human life, both before and after birth, both at the height of its potentialities and in the presence of malformations – every human life has received from God its dignity that no one can violate. Every man is made in the image of God!': John Paul II, 'Homily to the Sick and the Elderly, Salzburg Cathedral, 26 June 1988', n. 6.

[78] 'In truth life is a gift of God to men created in love in His image and likeness. This understanding of the sacred dignity of the human person leads to a giving of value to all the stages of life. This is a question of consistency and justice. Indeed, it is impossible truly to appreciate the life of an elderly person without truly appreciating the life of a child from the beginning of his or her conception. Nobody knows the point one will reach if life is no longer respected as an inalienable and sacred good: John Paul II, 'Message to the Participants at the World Assembly on Ageing of the Population, 22 July 1982'.

[79] John Paul II, 'Address to the Participants at the Convention on Life Organised by the Italian Bishops' Conference, 16 April 1989'.

[80] 'older people have a right to a place in society and even more so to *an honoured place within the family*. The family is called to be a communion of persons. It needs to be reminded of its special mission to foster, manifest and communicate love, and its duty to provide assistance to its weaker members, not least the elderly, and surround them with affection': the Pontifical Council for the Laity, 'The Dignity of the Older Person', 1998, III.

[81] Benedetto XVI, 'ai partecipanti alla XXII conferenza internazionale del Pontificio Consiglio per gli operatori sanitari, sul tema della pastorale nella cura dei malati anziani, Sala Clementina, sabato, 17 novembre 2007', *Dolentium Hominum*, n. 67, anno XXII, 2008 n. 1, pp. 7-8.

[82] *Ibidem.*

[83] 'The person called to accompany the aged sick must confront these questions, especially when there seems to be no possibility of healing. Today's efficiency mentality often tends to marginalize our suffering brothers and sisters, as if they were only a "weight" and "a problem" for society. The person with a sense of human dignity knows that they are to respect and sustain them while they face serious difficulties linked to their condition: 'Benedetto XVI, ai partecipanti alla XXII conferenza internazionale del Pontificio Consiglio per gli operatori sanitari, sul tema della pastorale nella cura dei malati anziani, Sala Clementina, Sabato, 17 novembre 2007', *Dolentium Hominum*, n. 67, anno XXII, 2008 n. 1, pp.7-8.

[84] 'Indeed, recourse to the use of palliative care when necessary is correct, which, even though it cannot heal, can relieve the pain caused by illness': 'Benedetto XVI, ai partecipanti alla XXII conferenza internazionale del Pontificio Consiglio per gli operatori sanitari, sul tema della pastorale nella cura dei malati anziani, Sala Clementina, Sabato, 17 novembre 2007', *Dolentium Hominum*, n. 67, anno XXII, 2008 n. 1, pp. 7-8.

[85] John Paul II, 'Letter to the Participants at the Second World Assembly on ageing, 3 April 2002': *La dignità della persona anziana*, *Enchiridion Vaticanum* 21, 2992, Edizioni Dehoniane, Bologna, 2005, pp. 208-215, see nn. 262-263, p. 215.

[86] *Dolentium Hominum*, n. 67, anno XXII, 2008 n. 1, pp. 7-8.

[87] *Insegnamenti* VII,1, 1984, pp. 743-746, n. 3.

[88] *La dignità dell'anziano e la sua missione nella Chiesa e nel mondo*, III, Pontificium Consilium Pro Laicis, 1 ottobre 1998, *Enchiridion Vaticanum* 17, 1988, Edizioni Dehoniane, Bologna, 2000, pp. 1146-1173, see n. 1545 p. 1169.

[89] *Insegnamenti* VII, 1, 1984, pp.743-746, n. 4.

[90] *Evangelium Vitae* n. 67.

[91] ' You, dear brothers, well know by experience that technical services and health-care are not enough, even when they are carried out with diligent professionalism. A patient is a sick person and as such needs to feel the affectionate presence of those he loves and his friends. This presence is spiritual medicine that restores love for life and persuades us to fight with an inner strength which by no means rarely contributes in a decisive way to healing': John Paul II, 'Meeting with the Sick and the Elderly, Callao, Peru, 4 February 1985', n. 2.

[92] Benedetto XVI, ai partecipanti alla XXII conferenza internazionale del Pontificio Consiglio per gli operatori sanitari, sul tema della pastorale nella cura dei malati anziani, Sala Clementina, Sabato, 17 novembre 2007, *Dolentium Hominum*, n. 67, anno XXII, 2008 n. 1, pp. 7-8.

[93] 'Death is a part of our human horizon and provides to it its true and mysterious dimension. The contemporary world, above all the West, needs to learn to reinsert death in human life. Who can not wish for his fellow and wish for himself a welcoming and taking on of this last act of earthly life in dignity and serenity, which certainly possible for believers: Giovanni Paolo II, 'Messaggio all'assemblea mondiale sui problemi dell'invecchiamento della popolazione', Lunedi 26 luglio 1982, *Insegnamenti di Giovanni Paolo II*, 1982, V,3, Luglio-Decembre, pp.123-131, see pp.125.16.

[94] *La dignità dell'anziano e la sua missione nella Chiesa e nel mondo*, III, Pontificium Consilium Pro Laicis, 1° Ottobre 1998, *Enchiridion Vaticanum* 17, 1988, Edizioni Dehoniane, Bologna, 2000, pp.1146-1173, see n. 1545 p. 1169.

[95] Giovanni Paolo II, *Lettera agli anziani*, 10, *Enchiridium Vaticanum* 18 1989, Edizioni Dehoniane, Bologna, 2002, pp. 994-1035, see n. 1685, p. 1033.

PROLUSION

The Elderly Sick Person: a 'Challenge' for Pastoral Care in Health

HIS EMINENCE CARDINAL WILLEM JACOBUS EIJK,
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Once a year I give a talk within the framework of a post-university course for medical doctors that is offered by a research institute on ageing of the University of Leyden in Holland. This institute is called the 'Leyden Academy on Vitality and Ageing'. The director of this academy, Professor Rudi Westendorp, a geriatrician, has published a book on how attitudes to old age have changed since the complete transformation in the ages at which people die.[1] This book begins with the story of an undertaker in a Dutch village who on the evening of St. Sylvester's Day 1889 drew up for the mayor a list of all the people who had died and been buried in the local cemetery that year, The list involved 85 people, of whom 6 had been born dead, 27 had died during the first year of their lives and 6 had died before their first birthday. This means that almost a half of the people that this undertaker had buried had been breastfed babies or very young children. He was not surprised by these statistics. Seeing these facts every year, he had become used to them.

The Experiences of an Undertaker

His funeral parlour was made for numerous funerals of breastfed babies or very young children. In an outside shed there was a good supply of coffins for this category of people. For children, coffins were of the same size whereas those for adults had to be specially made by the undertaker.

In the1930s the undertakers were troubled because of a new trend. They pointed out that there was a decrease in the deaths of children whereas the number of funerals for elderly people was on the increase. During the same period the industrial production of coffins of different sizes began. Since there was no need for coffins that the undertakers produced in uniform batches for children, and the coffins for adults were produced in factories, the undertakers lost a large part of their income.

Starting in the 1930s showrooms were built where one could choose a coffin of the kind one liked and of the measurements that were required. However, there were almost always only coffins for adults. However there were almost only coffins for adults. There was a lack of supply of coffins for breastfed or very young children because this was no longer necessary. No undertakers was organised for the funeral of a very young dead person. Parents, who were no longer used to one their children dying at a young age, saw this almost as a scandal that should not occur. Recently, a Catalan carpenter told me that some years ago in the village where he lived a number of breastfed children suddenly died. The villagers immediately named their family doctor 'Herod', a reference to King Herod who killed the newborn babies of Bethlehem after the birth of Jesus in an attempt to eliminate him as a possible competitor for the throne.

The undertaker at the beginning could have predicted that evening of St. Sylvester's Day how many people belonging to certain categories would have died the following year, that is to say in the year 1890. This could have been done in each family given that people were aware that death did not stop with elderly people but could also befall young people and very children. The death of a young child was certainly a source of sadness but it was not seen as an overwhelming scandal because it was a frequent phenomenon.

Not so long ago elderly people were seen as people who had achieved something, that is to say they had reached an old age. How was this possible? What was their secret? Elderly people were seen with a mixture of jealousy and admiration. On the whole, elderly people were greatly esteemed. For example, many texts in Holy Scripture bear witness to this attitude and encourage it.[2]

Nowadays we have to deal with a very different attitude. To become an elderly person is no longer an achievement and few people want to know the secret of how one can become elderly. We only want to know the secret of an elderly person who manages to appear young. The elderly person is no longer the object of admiration. Quite the contrary, Young or middle-aged people in the Western world, but also in other parts of the world which are characterised by a rapid growth in prosperity, when they see an elderly person often think spontaneously: 'I don't want to become like that'. And we have a large number of ways of preventing the ageing process. Much improved and rich nutrition, as long as it is not superfluous, and the fact that a great deal of jobs involving manual work are now much lighter than before, have as a consequence the fact that many people, of an advanced age as well, seem much younger in their appearance than was the case not many years ago. This phenomenon has been further strengthened by the fact that many elderly people no longer dress as elderly people but like young people. A large number of cosmetic products are also used by men to conceal their age. In addition, an increasing number of people use plastic surgery to make themselves appear younger and in various different contexts this is done by people to have greater chances of advancement in their professional lives.

In general, most people do not have important medical problems before the age of fifty and manage to keep distant physical ills that endanger life until the age of sixty-five. Perhaps in the future this will be extended to the age of seventy-five. For example, the recent levels of mortality caused by heart disease are now less than half of what they were in many countries of the European Union both amongst the younger adult age bands and in the population as a whole.[3] As a consequence, not only in the case of incurable illnesses in children and young people but also those in individuals under the age of sixty-five, there is a certain tendency to see a physical malady as a scandal in the final analysis as unacceptable, because it should not occur at that stage of life. The consequence of this is an incapacity to integrate suffering when it finally arrives in life.

The whole of this development has two principal repercussions. First of all for the way in which an elderly sick person sees himself or herself, experiences his or her illness and assesses the value and dignity of his or her life. Secondly, for the way in which a medical doctor, nurse, pastor of souls and other health-care workers see the patient.

The Self-Image of an Elderly Sick Person

In contemporary secular culture, which is increasingly spreading throughout the world, how does a sick elderly person see himself or herself? Contemporary secular culture is described by sociologists and philosophers as the culture of expressive individualism and authenticity[4] which became a mass phenomenon in the Western world following the rapid growth in prosperity which enabled the individual to live in a way that was less dependent on other people. This culture involves not only the right but also the duty of an individual to stand out from others through his or her appearance, beliefs, philosophy of life or religion and the ethical values that he or she has chosen. Popularly formulated, the ideal is 'I want to be myself'. Three elements characterise this culture: [5] 1. autonomy: the individual himself or herself must determine his or her own life; 2. the creativity of the person in the sense of a development of himself or herself – within this self-development there stands out a strong orientation towards the emotions, which is characteristic of a profoundly empiricist culture: the criterion is not what is thought of a certain phenomenon or idea but 'if one feels good with it'; and 3. the individual must be original and unique but not a sheep.

The strong emphasis placed on the autonomy of the individual is accompanied by a vision of the human being that is profoundly dualistic. This sees rational consciousness, which is in substance reduced to the complex functions of the higher structures of the brain, which is specific to the human being, as the person in a true sense, but, on the other hand, sees the body as something that is extrinsic and with a purely instrumental value. The combination of these factors means that the value of life is seem as something to be assessed solely by the individual in question.

This culture of expressive individualism and authenticity is perhaps fascinating above all for young people but it is less so for elderly people, certainly when they are sick. The ideal of autonomy is based above all else on a negative idea of freedom, that is to say freedom understood as a protection against external limits: constraints imposed by the law or other people and by social pressure. An illness, and above all a chronic or incurable illness, is seen as a limitation of autonomy and of self-development, which is seen as a duty. This is the reason why, as I have already observed in this paper, many young people and middle-aged people, when they see an elderly sick person or a handicapped person, involuntarily think: 'I don't want to become like that'. A difficult point here is the orientation towards feelings in self-development. Feelings are very changeable but at certain moments they can be so overwhelming that the sick person is convinced that his or her life has lost all value. With this approach, an increasing number of sick people choose an end to their lives in the form of euthanasia or medically assisted suicide. However, believers as well can struggle with temptations of this kind, even saints, such as St. Therese of Lisieux. She confessed this to a sister of her Order during her night of faith when she was about to die, undergoing a very painful death by suffocation and by pleurisy caused by pulmonary tuberculosis: '*She did not know*, it escapes her, *what suffering in that way meant*. And she warned 'that poisonous medicines for external use should not be left near her, advising that they should never be left near to sick people who were suffering so much that they had lost their wits'. This is what she repeated three days before her death to Sister Mary of the Trinity: 'O! If I did not have my faith, I could never bear so much suffering. I am amazed that amongst those who do not have faith there are not more who take their own lives'.[6]

Against the background of this culture that I have described it is not easy to proclaim the doctrine of the Church on this subject, a doctrine which holds that human life has a universal dignity which transcends every condition of life, feelings and assessments that the individual concerned may have as regards his or her life. This universal dignity, which can also be demonstrated in a philosophical way, derives in theological terms from the fact that man is created in the image and likeness of God (cf.

Gen. 1:26-27; 9:6). This concerns the person in his or her totality, in his or her spiritual dimension and in his or her material dimension. The Second Vatican Council affirmed this conviction with the following words: ‘Though made of body and soul, man is one. Through his bodily composition he gathers to himself the elements of the material world; thus they reach their crown through him, and through him raise their voice in free praise of the Creator. For this reason man is not allowed to despise his bodily life’ (*Gaudum et spes* n. 14).[7] And in his encyclical *Evangelium Vitae* Pope John Paul II wrote that human life is always a good: ‘in man there shines forth a reflection of God himself’ (*Evangelium Vitae* n. 34).[8] This, which everywhere and always applies, however much life may be attacked or disfigured by an illness or a handicap, is the foundation of the universal dignity of the human being.

Christian faith adds to all of this a further special dimension. In suffering, however much it may put under pressure the capacity of a sick person to see the dignity of his or her own life, one can reveal a deeper meaning of human life in the form of a call by Jesus, which John Paul II formulated in *Salvifici doloris* in the following way: ‘Christ does not explain in the abstract the reasons for suffering, but before all else he says: “Follow me!”. Come! Take part through your suffering in this work of saving the world, a salvation achieved through my suffering! Through my Cross. Gradually, *as the individual takes up his cross,* spiritually uniting himself to the Cross of Christ, the salvific meaning of suffering is revealed before him. He does not discover this meaning at his own human level, but at the level of the suffering of Christ. At the same time, however, from this level of Christ the salvific meaning of suffering *descends to man’s level* and becomes, in a sense, the individual’s personal response. It is then that man finds in his suffering interior peace and even spiritual joy’ (*Salvifici doloris*, n. 26).[9]

The great question is: how can one convince the sick person and above all else a sick elderly person of the intrinsic universal dignity of his or her life? One understands that a critical analysis of contemporary secular culture is required, although this is not sufficient, not least because the culture of individualism and authenticity is accompanied by little interest in the opinions of other people. What contemporary culture is really interested in is the biographies of individuals, when a religious subject is involved as well. Whereas a theological explanation should not expect to attract great interest, many people want to know how faith works in the life and the experiences of an individual.

In this field the elderly sick person himself or herself has the task of convincing other people of the universal dignity of human life in all circumstances. One could perhaps think that this task falls first and foremost to health-care workers and one understands that this is an essential part of their role. However, even though an elderly sick person is no longer capable of a series of activities, this does not condemn him or her to mere passivity. An elderly sick person, especially if he or she is able to see the universal dignity of human life and thus also that of his or her own life and to find in this great strength, can be a convincing witness to this for other people.

In this context one can but think of the words of Pope John Paul II, whose words I quoted above. During the last years of his life he suffered from Parkinson’s disease which increasingly deprived him of the capacity to move and to express himself through speech and facial expressions. Despite this fact, he did not hesitate to show himself in public. In this way, by demonstrating that a handicapped person can remain a leader at a world level, he encouraged a large number of sick elderly people not to lose from sight the dignity of life, in the circumstances in which they lived as well. During the last part of his life John Paul II applied his apostolic letter *Salvifici doloris*, which I quoted above, to himself. Andrea Mariani thus speaks about a ‘lived magisterium’.[10] In his homily on the occasion of the celebration of the jubilee of the year 2000 of the sick and health-care workers of 11 February 2000, he enjoined all sick people to do the same because our epoch has need of this: ‘The Church enters the new millennium, clasping to her heart the Gospel of suffering, which is a message of redemption and salvation. Dear sick brothers and sisters, you are exceptional witnesses to this Gospel. The third millennium awaits this witness from suffering Christians’.[11]

The Attitude of Health-Care Workers to Sick Elderly People

The second question on the other side of the coin of that discussed hitherto in this paper is the following: how do health-care workers see sick elderly people? Given the approach of contemporary culture, which has been described above, it may happen that a health-care worker, when he or she sees an elderly person and above all a sick elderly person, spontaneously thinks: ‘I don’t want to become like that’. However understandable this may be within the context of the contemporary tendency to worship youth and a beautiful, slender, strong and healthy body, this approach, even where the health-care worker concerned strives not to show it or even is not aware of it, can be perceived consciously or otherwise by the sick elderly person who has been entrusted to his or her care. This will not help the sick elderly person to discover or rediscover the dignity of his or her life. Indeed, it may even reinforce the image that he or she has of himself or herself under the influence of contemporary culture and his or her own physical state.

First of all, the health-care worker should provide sincere care to the human person in his or her totality, demonstrating a human interest in the patient, whether young or old, which goes beyond the purely medical-technical side of things. If the health-care worker focuses too much on the medical-technical side of things this can lead to a sense of failure when something cannot be done at this level. For this reason, the work of a health-care worker runs the risk at times of not paying sufficient attention to an elderly sick person who is often afflicted by chronic or incurable illnesses.[12]

The general experience of centres for palliative care is that patients with an incurable illness, even if it cannot be cured, revive after being admitted. These patients feel affirmed in their human dignity. A very important element in the concept of palliative care is that it involves total care for the human person, one that is human, psychological, social and spiritual and is offered by an institution that functions as a community of patients and helpers in an atmosphere of interpersonal relationships that are open to trust.[13]

One readily understands that this upholding of the human dignity of the sick elderly person is achieved in a more fecund way by a health-care worker who has himself or herself struggled to have his or her own dignity recognised, whatever the cause may have been. It is not possible to place oneself totally in another person's shoes. This requires experience and maturity which enable the health-care worker himself or herself to look into the eyes of the existential threats to the recognition of his or her own human dignity. For that matter, a health-care worker can learn a great deal about an elderly sick person who appears to be able to recognise his or her human dignity, even though this last is tested.

It is not possible to put oneself totally in the shoes of another person. This requires experience and maturity. Whatever the case, the contemporary health-care worker has the urgent task of being aware of the possible risk, which is implicit in the culture of expressive individualism, to see illnesses and handicaps above all during old age as a limitation of autonomy and this of dignity of one's life. It is not easy to withdraw from the culture in which one has grown up and in which one lives. Here, too, the motto written on the temple of the Oracle of Delphi applies: 'know yourself' (γνῶθι σεαυτόν, *gnôthi seautón*). Once we have become aware of our own attitudes we are able to make a choice that involves 'changing our direction'. This requires a clear view of contemporary culture and of the strong influence that it has on our attitudes, as well as a firm decision at the level of will by which we can guide our interior lives.

A strong source of inspiration for health-care workers is an icon, just as John Paul II is an icon for all suffering sick people. An icon in Eastern-Orthodox Christianity is an image that makes something of the person portrayed actually present. By analogy a person who is an icon makes a special excellent characteristic present in his or her being and actions, and is thus seen as a model to follow in a certain specific context.

The supreme icon for Christian health-care workers is the Good Samaritan as described in the parable told by Jesus in the Gospel according to St. Luke (10:25-37).[14] After seeing the wounded man who had been attacked by robbers at the side of the road, the Good Samaritan, unlike the Levite and the priest, does not take a new direction to avoid meeting the victim of this episode. He makes his heart, which is full of mercy, talk. He does not hesitate to help him, even though the man is in trouble, is not attractive and is repugnant to look at. The Good Samaritan is not able to return the possessions of his that have been stolen but he does do something which is more important and essential in that situation: in helping the wounded and robbed man he recognises the dignity of that wounded and robbed man and helps him to discover anew his own his own dignity as a human being.

A notable element in this parable is that is communicated by Jesus in response to the question posed to him by the doctor of law: "And who is my neighbour?" (Lk 10:29). At the end of the parable Jesus turns round the question and asks: "In your opinion, which of these three acted like a neighbour towards the man attacked by robbers?" (Lk 10:36). The wounded man is not described as a neighbour, as one could have expected from the first question: it is the person who provides help who is described as such. This help concerns not only the physical aspect but also the human person in his or her totality, as a result of which one can help him or her to rediscover his or her human dignity which is often lost from sight given existential threats to life and health. This parable asks us to be ready to makes ourselves a neighbour to a person in need.

The figure of the Good Samaritan acquires an extraordinary meaning when we follow the interpretation of this parable that was offered by some of the Fathers of the Church who identified him with Jesus Christ. [15] Christ, in making himself man, became a neighbour to us to redeem us from sin, to restore our dignity as beings created in the image of God and to raise us to the dignity of being sons adopted by God. Since he remedied our relationship with God, a large number of Fathers of Church bestowed upon him the epithet of '*Christus Medicus*'.[16]

The parable of the Good Samaritan involves a message with a special meaning for those who belong to the culture of expressive individualism. The doctor of the law, in asking 'who is my neighbour?', and defining himself as the person who provides help and the person in need as his neighbour, places himself as a helper at the centre of everything. However, the parable is told from the point of view of the person who has become the victim of robbers. The parable in an implicit way invites those who listen to it, including the doctor of law, to place themselves in the position of the victim. The wounded man is placed at the centre of the movements of he who is ready to make himself his neighbour. Rather than placing his own ego at the centre of things through the question as to who is the object of love for neighbour, Jesus enjoins us to place at the centre of things the person who is need of help, becoming a neighbour to anybody who is in need. A person who helps another person must be careful not to put himself or herself at the centre of the circle, seeing the sick person as an object who is in need of his or her benevolent help. The parable of the Good Samaritan invites us to invert the roles: to respect the central place of the sick person in the health-care world not as an object but as a subject of medical care for whom the health-care worker becomes a neighbour. Making oneself a neighbour to a sick person out of love intrinsically implies a recognition of his or her human dignity.

A contemporary icon for health-care workers, who imitated '*Christus Medicus*' in his professional life as a medical doctor, was St. Giuseppe Moscati (1880-1927), an internist and lecturer in physiology at the University of Naples during the first quarter of the last century.[17] This medical doctor, who was famous for his diagnostic abilities, practised medicine with great love and with great dedication to his patients. He was a friend of patients of any social class, even of those who could not pay for his services. In his patients he recognised something of the suffering figure of Christ (Mt 25:31-46) and thus a dignity that went beyond the purely human level. For their part, his patients recognised something of Christ the Physician in him. Living in a very modest way, he expressed solidarity towards his patients in a way that was professionally thought through. His action was penetrated by Christian humility in the form of an approach of kindness. By this Moscati demonstrated that he recognised the human dignity of all his patients and helped them to (re)discover it.

An event that was very characteristic of his life as a medical doctor took place in the year 1906 on the occasion of the eruption of Vesuvius. Everyone tried to flee from the threatened district of Naples which had a hospital, whose patients ran the risk of buried together with the hospital under the debris of lava and ashes that was falling from the sky. Moscati did not hesitate to go to the hospital and to attend to the evacuation of the hospital, even taking with him patients who were gravely ill. Immediately after he had left the hospital, the roof of the building collapsed under the weight of the ash and lava. The rescue operation by which all of the patients were saved took twenty hours. Moscati engaged in this enormous effort 'amidst the scepticism of those who believed for these old people nothing could be done'. [18] In doing anyway this he demonstrated that the human dignity of these elderly patients was everything for him. He made himself their neighbour both in extreme conditions and in those of normal everyday life.

Epilogue

Both patients and health-care workers have their own active role to play in upholding the human dignity of sick elderly people. Both, in folding in on themselves as individuals, do a wrong to the development of an interpersonal relationship which is essential in recognising one's own dignity as well as that of other people. This means that implicit in the culture of expressive individualism and authenticity there is a risk above all else for sick elderly people. In order to avoid this, and to find a productive pathway, the Church points out to us many icons which are different from each other but which can be well suited to the special features of one's own character and one's own personal activities. All of these icons, however, are based upon the icon that is fundamental both for a sick person and for a health-care worker – Jesus Christ, the celestial physician, who through his suffering heals the human person in his or her totality.

Notes

[1] Rudi Westendorp, *Oud worden zonder het te zijn: Over vitaliteit en veroudering* (Amsterdam/Antwerpen: Atlas Contact, 2014), pp.128-131.

[2] Leviticus 19:32: 'Show respect for old people and honour them. Reverently obey me; I am the Lord'; Proverbs 16:31: 'Long life is the reward of the righteous; grey hair is a glorious crown'; Proverbs 20:29: We admire the strength of youth and respect the grey hair of age'; 1 Tim 5:1: 'Do not rebuke an elder man, but appeal to him as if he were your father'.

[3] M. Nichols, N. Townsend, P. Scarborough and M. Rayner, 'Trends in age-specific coronary heart disease mortality in the European Union over three decades: 1980-2009', *European Heart Journal* 34 (2013), pp. 3017-3027.

[4] C. Taylor, *Varieties of Religion Today: William James Revisited* (Harvard University Press, Cambridge/London, 2002), pp. 79-107.

[5] H. Zondag, 'Expressief individualisme en religie', *Religie & Samenleving* 4 (2009), n. 1, pp. 16-36.

[6] Teresa di Lisieux, *Storia di un'anima* (Città Nuova, Rome, 1997), Epilogo dello Scritto Autobiografico C, diretto a madre Maria di Gonzaga, p. 281.

[7] Concilio Vaticano II, 'Costituzione Apostolica *Gaudium et Spes*', *AAS* 58 (1966), pp. 1025-1115, quotation p. 1035.

[8] Giovanni Paolo II, 'Lettera Enciclica *Evangelium vitae* (25 marzo 1995)', *AAS* 87 (1995), pp. 401-522, quotazione a p. 439.

[9] Giovanni Paolo II, 'Epistola Apostolica *Salvifici doloris* (11 febbraio 1984)', *AAS* 76 (1984), pp. 201-250, quotation p. 241.

[10] Andrea Mariani, *Giovanni Paolo II e la sofferenza: Un magistero vissuto* (Cantagalli, Sienna, 2011).

[11] Giovanni Paolo II, 'Omelia per il Giubileo dei malati e degli operatori sanitari (11 febbraio 2000)', n. 5, veda: http://www.vatican.va/holy_father/john_paul_ii/homilies/2000/documents/hf_jp-ii_hom_20000211_jubilee-sick_it.html).

[12] Cf. R. Janssens, *Palliative care: Concepts and Ethics* (Nijmegen University Press, Nijmegen, 2001), p. 40.

[13] S. du Boulay, *Cicely Saunders; een leven voor stervenden* (Buijten & Schipperheijn, Amsterdam, 1984), pp. 58-62 (original text: *Cicely Saunders: Founder of the Modern Hospice Movement*, Hodder and Stoughton, London, 1984).

[14] Cf. W.J. Eijk, 'The Good Samaritan is the Greatest Justice', *Dolentium Hominum* 15 (2011), n. 1, pp. 64-68.

[15] Cf. *ibid.*, pp. 64-65.

[16] Cf. H. Schipperges, ‚Zur Tradition des 'Christus Medicus' im frühen Christentum und in der älteren Heilkunde', *Arzt und Christ* 11 (1965), pp. 16-19.

[17] G. Infusino, *Un santo in corsia. Giuseppe Moscati* (Edizioni Paoline, Cinisello Balsamo, Milan, 1987); G. Papàsogli, *Giuseppe Moscati. Das Leben eines heiligen Arztes* (Christiana-Verlag, Stein am Rhein, 1982).

[18] *Ibid.*, p. 62.

Sick Elderly People in Holy Scripture: ‘They still bear fruit in old age and are always green and strong (Ps 92:14)

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A sick man is a man who is not in good health. Illness affects the body or the spirit. It can affect both at one and the same time. In such a case reference is made to a psycho-somatic illness. An elderly person is a person of an advanced age, an old person. Demographic studies define people who are sixty or over as being elderly.[1]

In my paper we will see how Holy Scripture sees sick elderly people. We begin with Holy Scripture because the Bible is its foundation, the basis of reflection on every discourse or every question that bears on faith and morality for Christians. Every study draws on the spring of Holy Scripture.

For our subject we will begin with verse 15 of psalm 92: ‘They still bear fruit in old age and are always green and strong (Ps 92:14). This psalm is a hymn of praise to God. This hymn praises the Lord for his wonders, his works, and compares the destiny of the wicked with that of the just man. Thus it is that the last verses of this psalm sing the destiny of the just man: ‘The righteous will flourish like palm trees; they will grow like the cedars of Lebanon. They are like trees planted in the house of the Lord, that flourish in the Temple of our God, that still bear fruit in old age and are always green and strong. This shows that the Lord is just, and there is no wrong in my protector’ (Ps 92:13-16).

Starting from this passage, I will address the subject of the sick elderly person in Holy Scripture. My analysis revolves around three points. The first describes the weaknesses of sick elderly people. The second looks at the strengths of sick elderly people. The third proposes the approach that should be adopted in relation to sick elderly people.

1. The Weaknesses of Sick Elderly People

According to Biblical thought, illness is a punishment that comes from God. God punishes the sinner and rewards the just. For example, the friends of Job declare that his illness has its origins in the sins that he has committed. ‘Eliphaz of Teman spoke next. He said: can a human being contribute anything to God, when even someone intelligent can benefit only himself? Does Shaddai derive any benefit from your uprightness, or profit from your blameless conduct? Do you think he is punishing you for your piety and bringing you to justice for that? No, for your great wickedness, more likely, for your unlimited sins! You have exacted unearned pledges from your brothers, stripped people naked of their clothes, failed to give water to the thirsty and refused bread to the hungry; handed the land over to a strong man, for some favoured person to move in, sent widows away empty-handed and crushed the arms of orphans. No wonder, then, if snares are all around you, and sudden terrors make you afraid’ (Job 22:-10). In the Gospel according to St. John the disciples ask about the man born blind: ‘Teacher, whose sin caused him to be born blind? Was it his own or his parents’ sin?’ (Jn 9:2).

But this approach is called into question by the suffering of the just. A just man also falls sick or suffers. ‘You, who enquire into my faults and investigate my sins, you know very well that I am innocent, and that no one can rescue me from your grasp’, Job says to God (Job 10:6-7). Indeed, the just suffer while the impious prosper. The suffering of the just remains a mystery. The solution is to hope in, and to have trust in, God, whose wisdom is greater than that of man.[2]

In such a context we encounter the sick elderly person who is losing all his strengths. Here is a pathetic text that portrays him: ‘Remember your Creator while you are still young, before the bad days come, before the years come which, you will say, give you no pleasure; before the sun and the light grow dim and the moon and stars, before the clouds return after the rain; the time when your watchmen become shaky, when strong men are bent double, when the women, one by one, quit grinding, and, as they look out of the window, find their sight growing dim. When the street-door is kept shut, when the sound of grinding fades away, when the first cry of a bird wakes you up, when all the singing has stopped; when going uphill is an ordeal and you are frightened at every step you take – yet the almond tree is in flower and the grasshopper is weighed down and the caper-bush loses its tang; while you are on the way to your everlasting home and the mourners are assembling in the street; before the silver thread snaps, or the golden bowl is cracked, or the pitcher shattered at the fountain, or the pulley broken at the well-head: the dust returns to the earth from which it came, and the spirit returns to God who gave it’ (Eccl

12:1-7). This text is an allegory of old age which is compared to a home, to domestic life and to the season of winter.

Indeed, the watchmen of the home are hands, the strong men are legs, the grinding is done by teeth, eyes look out, eyes are the street-door, the millstone is the mouth, the cry of the bird is hearing, the almond tree in flower refers to grey hairs, the grasshopper refers to feet, the caper-bush alludes to the strength of the libido and the everlasting home is the grave. The golden bowl that cracks with the snapping of the silver thread, like the pitcher that is shattered at the fountain and like the pulley that is broken, are images of death. Thus it is that in old age many of the faculties of man are lost. A person's hands and feet become weak, they are bent and tremble, teeth fall out or no longer have the strength to chew food, a person's eyes no longer see clearly, lips tremble, the voice grows weaker, ears no longer hear well, sleep becomes short and the person gets up early with the dawn chorus. A person becomes afraid of going uphill because the heart beats and there is tiredness, he or she afraid of walking because of dizziness, his or her hair becomes white or falls out, feet become swollen or become weak, the libido decreases, the stimulus of the caper no longer has its effect and finally the heart stops beating, just as all domestic activity stops.[3]

Thus it is that the life of an elderly person, like every other life, ends in death. Every creature dies. Man is dust. He came from dust and he will return to dust (Gen 2:7 and 3:19; Ps 103:14; Eccl 3:19-20). He can be compared to grass or to the flowers of the fields that soon wither (Ps 90:5-6; Job 14:2), to a breath (Ps 62:10) and to a shadow (Ps 39:5-7). Indeed, man has a short life. Seventy years are enough for him; he reaches the age of eighty if he is in good health: 'Seventy years is all we have – eighty years if we are strong; yet all they bring us is trouble and sorrow; life is soon over and we are gone' (Ps 89:10).

And yet despite all these weaknesses connected with old age and the death of every creature, some strengths are attributed to the sick elderly person.

2. The Strengths of Sick Elderly People

The strengths or the values of the sick elderly person belong to the context of reward for the just. According to Deuteronomy, the man who is just, that is to say the man who aligns his life with the will of God, is rewarded. Instead, the man who is unjust receives a punishment from God (Dt 28:1-46). Justice, that is to say wisdom, leads to happiness, and inequity, that is to say folly, leads to ruin. It is God who rewards the good and punishes the wicked (Prov 3:33-35; 9:6 and 18).

Thus the just man, in illness and old age as well, bears much fruit, as I will now show in this sub-section. Hagiographers use plant terms to express the fruits of old age. 'The righteous will flourish like palm tress; they will grow like the cedars of Lebanon. They are like trees planted in the house of the Lord, that flourish in the Temple of our God, that still bear fruit in old age' (Ps 92:13-15). The palm is a tree of a fine shape. It symbolises the beauty of the justice of man. The cedar is a tree that lives for a very long time, indeed for more than a thousand years. It symbolises that long life that generates wisdom. These trees, in old age, continue to bear fruit, conserving their youth, given that they are always green, and their vigour. These terms are significant in the contest of an arid country such as Palestine. In a country of thirst, water has greater value; in the soil of a desert growth and the green colour of the vegetation express more emphatically the value of a man, above all the case of an elderly man.[4]

Many similar passages with the same term express the same idea as regards the wise and just man. 'They are like trees that grow beside a stream that bear fruit at the right time, and whose leaves do not dry up. They succeed in everything they do (Ps 1:3). 'They are like trees growing near a stream and sending out roots to the water. They are not afraid when hot weather comes, because their leaves stay green; they have no worries when there is no rain, they keep on bearing fruit (Jer 17: 8). 'And I will always guide you and satisfy you with good things. I will keep you strong and well. You will be like a garden that has plenty of water, like a spring of water that never runs dry' (Is 58:11).

Wisdom also grows like that plants that have just been mentioned: 'I grew tall, like the cedars in the Lebanon, like the cypresses on Mount Hermon,, like the palm trees of Engedi, the like the roses of Jericho, like beautiful olive trees in the fields, like plane-trees growing by the water (Sir 24:13-14).

In such a thematic context, an elderly person brings with him or her the fruits of wisdom, which is also expressed with a vocabulary of vegetation and fertility: life, branches, the tree of life, springs, deep and flowing water. The life of a wise person is long and grey hair is a glorious crown (Prov 16:31); the just will be as green as leaves (Prov 11:28); the fruit of the just is the tree of life, a wise person wins over souls (Prov. 11:30); the teaching of a wise person is a source of life and avoids the snares of death (Prov 13:14); for those who possess it prudence is a spring of life (Prov 16:22); and the words of the mouth of a man are deep water, the source of wisdom is a flowing stream (Prov 18:4).

The Lord assures the wise man that he will have strength and youthfulness: 'He fills my life with good things, so that I stay young and strong like an eagle' (Ps 103:5). To live a long time is a sign of the blessing of the Lord: 'Like wheat that ripens till harvest time, you will live to a ripe old age' (Jb 5:26).

This fertility of man is the product of his justice. And it is because he practises justice that man is fertile. A just man enjoys prosperity, riches and wellbeing. Justice generates fertility.[5] God requires of man the fruits of justice (Is 5:2). Indeed, it is he who makes the land fertile and makes all forms of justice sprout (Is 55:10-11; 61:11).

This means that a just man, even when he grows old, still bears fruit at all levels: the biological, the spiritual, the sapiential and the moral.

At a biological level, for example, a man has a period of fertility that is longer than that of a woman. A man aged eighty can generate a son. And of him one can say, according to our psalm, that he will 'still bear fruit in old age and is always green and strong' (Ps 92:15).

At a spiritual level, the fruit that the elderly person bears is advice. In the Bible the old person is seen as being wise. Old age is a symbol of justice and wisdom. 'Long life is the reward of the righteous; grey hair is a glorious crown' (Prov 16:31). An old man is seen as a person who must have these qualities of wisdom and being able to teach: 'Older men should be reserved, dignified, moderate, sound in faith and love and perseverance. Similarly, older women should behave as befits religious people, with no scandal-mongering and no addiction to wine -- they must be the teachers of right behaviour and show younger women how they should love their husbands and love their children, how they must be sensible and chaste, and how to work in their homes, and be gentle, and obey their husbands, so that the message of God is not disgraced' (Tt 2:2-5).

As is the case with the Bible, in contemporary culture many proverbs demonstrate the sapiential role of the elderly in society. Let us remember some of them. 'When an old man dies, a whole library burns' (Hamadou Hampateba). This means that an old man has a great deal of knowledge that he can share. He has the experience of a long life that he can share with other people. His death is a loss for those who survive him. 'An old man should not be absent from home'. This means that there must be an old person to give advice. 'If a young man is absent, the person to be sent out (to work) is absent; if an old person is absent, advice (an adviser) is absent. The value of an elderly person lies in being able to give advice. 'The mouth of an elderly person has bad breath, and yet he says good things': an elderly person gives good advice even though it is difficult to accept it and put it into practice.

Lastly, the fecund life of an elderly person opens up to immortality. The death of a just man is not a punishment of God, as is it for bad people, but openness to eternal life: 'For God created human beings to be immortal, he made them as an image of his own nature…But the souls of the upright are in the hands of God, and no torment can touch them. To the unenlightened, they appeared to die, their departure was regarded as disaster, their leaving us like annihilation; but they are at peace. If, as it seemed to us, they suffered punishment, their hope was rich with immortality (Wis 2:23; 3,1-4 ; cf. Deut 12:2-3). The just survive through their descendants. Memories of their lives remain for ever. They will be remembered as a blessing (Prov 10:7).

Knowing the strengths and the weaknesses of sick elderly people, we can now define in the final sub-section of this paper the behaviour that should be adopted towards them.

3. The Approach that should be Adopted towards Sick Elderly People

The approach that one should adopt towards a sick elderly person is one of respect and understanding. This goes back to the fourth commandment of the Decalogue: 'Respect you father, and your mother, so that you may live a long time in the land that I am giving you' (Ex 20:12; cf. Eph 6:1-3; Col 3:20).[6]

An elderly person should be respected and he or she should not be mocked: 'Never think less of someone because he is old; some of us are growing old, too' (Sir 8:6). Above all else, one should never laugh at a sick elderly person because he or she has one of those neurodegenerative diseases which are the subject of this international conference. We may cite for example the case of memory loss: 'My son, take care of your father when he grows old; give him no cause for worry for as long as he lives. Be sympathetic even if his mind fails him; do not look down on him because you are strong and healthy' (Sir 3:12-13). Indeed, one should always listen to the advice of an elderly person: 'Pay attention to what old people say, for they learnt from those who came before them; You can learn from them, and they can teach you how to have an answer ready when you need one'(Sir 8:9).

Lastly, as should be done with all sick people, elderly people should be cared for and prayed for (Jm 5:13-16). This is the New Testament foundation of pastoral care in health.[7]

Conclusion

To end this paper of mine, we can say that illness is a mystery. It seems to be a punishment of God, but it is God who heals, blesses and calls man to immortality.

An elderly person, even if he or she is sick, brings the blessings that are characteristic of a just man: he remains green and bears fruit. This fruit is the biological fertility that he can have, the wisdom of which he is a model, the advice that he can give, the experience of life that he can share, and so forth.

Thus an elderly person should be respected according to the fourth commandment and because he or she still has a great deal to teach us, through his or her mere presence as well. When we see an elderly person, even though that person may be very tired and sick, we have must ourselves: will I be also be able to reach the age of this person? We are not certain that we will reach old age. Old age, despite its difficulties, remains a blessing of the Lord. ■

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Notes

[1] Cf. Souiah, S.-A. and Toutain, S., *Analyse démographique et spatiale* (Editions du Temps, Nantes, 2005), pp. 154-156.

[2] Cf. Rad, G. von, *La sapienza in Israele* (Marietti, Genoa, 1990), pp. 184 and 187 and Auneau, J., *Les Psaumes et les autres écrits*, Petite Bibliothèque des Sciences Bibliques (AT 5, Desclée, Paris, 1990), p. 112.

[3] Cf. *La Bible de Jérusalem* (Cerf, Paris, 1998), p. 943; *La Sacra Bibbia. Edizione ufficiale della C.E.I.* (Conferenza Episcopale Italiana, Rome, 1987), p. 635; FESTORAZZI, F. *et al.*, *Il messaggio della salvezza. 5. Gli "scritti" dell'Antico Testamento* (Elle Di Ci, Leumann, Turin, 1990), p. 37 and RAD, G. von, *op. cit.*, p. 49.

[4] Cf. Kakule Vyakuno, J. E., *Question sociale et pratique religieuse à partir d'Is 58. Etude littéraire, théologique et historique. Tome I et II* (Thèse de doctorat en Théologie biblique, Institut Catholique de Toulouse, Toulouse, 1998), p. 349.

[5] Cf. *ibid.*, p. 351.

[6] Cf, *Catéchisme de l'Eglise catholique* (Mame et Plon, Paris, 1992), p. 451.

[7] Cf. Brown, R. E., *Que sait-on du Nouveau Testament ?* (Bayard, Paris, 2000), p. 791 and MARGUERAT, D.(ed)., *Introduction au Nouveau Testament. Son histoire, son écriture, sa théologie* (Labor et Fides, Geneva, 2000), p. 409.

FIRST SESSION

THE EPIDEMIC OF NEURODEGENERATIVE DISEASES AND HEALTH-CARE POLICY THE SILENT EPIDEMIC OF THE THIRD MILLENNIUM

1. Moral and Ethical Questions

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For a number of decades the incidence of neurodegenerative diseases has been steadily increasing and everything leads us to predict that this increase will continue, not only in developed countries but also in developing countries, with the steady ageing of their populations.

Faced with such an increase, the temptation will be increasingly great for States, ministries, institutions or health-care personnel to limit the access of people with such diseases to medical health services ('selective rationing') and to limit the number of these people through their elimination – euthanasia, assisted suicide or terminal palliative sedation. Thus it is of urgent importance today to counter these two temptations, meeting the epidemiological question of neurodegenerative diseases with realistic, ethical and effective short- or long-term proposals.

I will focus my attention on health-care proposals without going into questions relating to treatment or to medical and human care for patients with neurodegenerative diseases.

I. INTRODUCTION

A. General Observations

The general term 'neurodegenerative diseases'[1] is applied, in the form of an 'umbrella'[2] word, to a broad group of neurological disorders with heterogeneous clinical and pathological expressions that are caused by a 'neurodegeneration', [3] that is to say by the steady loss of the structure of neurons, including their death, without the cause of this loss being known. Since neurons do not reproduce and do not multiply, the organism is not able to replace them when they are damaged or when they die, and a progressive alteration of functions that were managed by these neurons follows, bringing about the gradual appearance of symptoms of a 'neurodegenerative disease'.

In general, these pathologies bilaterally attack a specific neuronal system, giving rise to a clinical set of clinical symptoms which is extremely variegated and which is expressed, according to the kind of disease involved, in cognitive deficits, dementia, alterations in movement and behavioural and psychological disturbances of varying degrees of gravity.

Neurodegenerative diseases are pathologies with an insidious beginning and a wounding and inexorably progressive development which is made clear when the damage to the patient is already at an advanced stage of his or her illness, precluding in almost all cases the possibility of an effective therapy. A steady loss of certain neurological functions takes place and they are debilitating and incapacitating.

Hitherto they have been treated with meagre results through the administration of purely symptomatic drugs and medicines.

1. Neurological disorders that are not neurodegenerative diseases

The following are not seen as neurodegenerative disorders: diseases of the nervous system that do not affect first of all the neurons, such as neoplasms, oedemas, haemorrhages or traumas of the nervous system; diseases of the nervous system that not involve the neurons themselves but their attributes such as the neurolemma in multiple sclerosis; peripheral diseases such as Charcot-Marie-Tooth diseases; [4] and pathologies in which neurons die as a consequence of a known cause, such as a hypoxia, poisoning, a metabolic defect or an infection (including prion diseases – spongiform encephalopathy or Creutzfeldt's disease and Jakob's disease).

2. Disorders that form a part of neurodegenerative diseases

There are hundreds of neurodegenerative diseases and many of these overlap, clinically and pathologically. This is something that makes their classification difficult.[5] The most common categorisation of neurodegenerative disorders is based upon their topography or their predominant alteration or often upon a combination of the two. Well defined different disorders are grouped together under the name of neurodegenerative diseases[6] and the most well known of these are: dementias, which include in particular Alzheimer's disease(AD) which is the most frequent of the neurodegenerative diseases and which is responsible for 60%-80% of these dementias and affects 7% of people over the age of sixty-five; Parkinson's disease, which affects about 1% of people over the age of sixty-five; Huntington's chorea, which has a prevalence of about 5-7 every 100,000);[7] amyotrophic lateral sclerosis (SLA) (Charcot's disease or 'Lou Gehrig's disease') (1.5-2.5 cases every 100,000 people a year);[8] and Friedrich's ataxia (spinocerebellar inherited ataxia), which has a prevalence of about 1 in 50,000.[9]

In this paper I will focus my attention on the two most frequent examples of neurodegeneration and which generate the gravest epidemiological and health-care problems, namely Alzheimer's disease and Parkinson's disease.

B. Dementias and Alzheimer's Disease

1. The various kinds of dementia

Dementias of old age or 'senile dementias', which afflict individuals of an advanced age, constitute the clinical entity that is most important as regards the various neurodegenerative diseases. Alzheimer's disease[10] is responsible for 60%-80% of these dementias and it is the most frequent of the neurodegenerative diseases.

In addition to Alzheimer's disease, the other dementias that make up this group are: the less debilitating form of Alzheimer's disease, with a prevalence of 2% to 5% in people over the age of sixty; vascular dementia, with a prevalence of 1% to 4% in people over the age of sixty-five;[11] dementia with Lewy bodies,[12] which is responsible for 15% to 20% of dementias in old age;[13] and frontotemporal dementia.[14]

2. Prevalence

The prevalence (the proportion of 'events' present in a population at a given moment) of Alzheimer's disease is estimated as being, according to the authors and the studies of the subject, between 1% and 13% of people above the age of sixty, with an average of 7%.[15] This prevalence doubles every five years of age after the age of sixty-five. Thus the percentage of people with Alzheimer's disease, which is 1% of people aged sixty, rises to 10% in people aged seventy and reaches 30% in people aged eighty-five.[16] 1,275 cases of Alzheimer's disease are identified every year in every 100,000 people over the age of sixty-five.[17] It afflicts 600,000 people in Italy, 300,000 people in France, and 4-5 million people in the United States of America.[18] In the year 2010 Alzheimer's disease affected 5.3 million people and cost 172 billion US$ in the United States of America.[19] At the present time in the world there are about 34 million people with Alzheimer's disease and it is calculated that the prevalence of this disease will triple over the next forty years.[20] The prevalence of this disease is lower (from 19% to 29%) in males than in females.[21] It is calculated that there are 7.7 million new cases of dementia every year in the world, that is to say a new case every four seconds.[22] The number of cases of dementia in the world is doubling every twenty years and it is thought that there will be 65.7 million cases by the year 2030 and 115.4 million by the year 2050.

3. Incidence

The incidence of dementias, that is to say the proportion of 'new events' that take place within a population during a certain period of time, increases in an exponential way with age – with no difference between the sexes – between the ages of 65 and 90,[23] and doubles every five years during these 25 years.[24] This increase in dementias with the age of an individual does not diminish after the age of ninety but continues in the same way.[25]

4. Risk factors

Alzheimer's disease is found in individuals that have an allele genotype apolypoprotein E and e4[26] and report a family history of dementia.

The appearance of Alzheimer's disease could be attributed, at a world level, according to Barnes and Yaffe (2011),[27] to the following factors: a low level of education (19% (6.6 million) (7.3% in the United States of America); smoking: 13.9% (4.7 million) (10.8% in the United States of America); physical inactivity: 13% (about 4.3 million) (21% in the United States of America); depression: 10.6% (almost 3.6 million) (14.7% in the United States of America); hypertension during adulthood: 5.1% (1.7 million) (8% in the United States of America); diabetes: 2.4% (825,000 cases) (3.3% in the United States of America); and obesity during adulthood: 2% (677,000) (7.3% in the United States of America). A combination of all these factors could be at work in 50.7% of cases of Alzheimer's disease, that is to say 17 million people.

If these factors could be reduced, one could prevent this disease in the world, according to Barnes and Yaffe, in the following ways: low level of education, reduced by 10%: 500,000 cases, reduced by 25%: 1.4 million cases; smoking, reduced by 25%: 1 million cases; physical inactivity, reduced by 25%: 380,000 cases; depression, reduced by 10%: 825,000 cases; hypertension, reduced by 10%: 40,000 cases; diabetes, reduced by 10%: 200,000 cases; obesity, reduced by 10%: 66,000 cases. Were there to be a reduction of 10% of all these factors: 1.1 million cases.

The hypothesis of a cognitive reserve (CR) or brain reserve capacity postulates that the mind can put up resistance to brain damage. This hypothesis has been advanced to explain cases where the disorders manifested by patients with Alzheimer's disease are lower than the lesions highlighted at a neuropathological level imply.[28] This hypothesis explains why individuals with a high level of education, with a high IQ, and a higher level social occupation,[29] run a lower risk of developing dementia.[30] In contrary fashion, less years of education[31] or a low educational level increase the risk of dementia (O.R = 2.61 for prevalence studies and 1.88 for incidence studies).[32]

5. The evolution of Alzheimer's disease

Alzheimer's disease causes a growing cognitive deterioration where memory deficit has a primary importance.

Alzheimer's disease, in general, has a covert beginning: people begin to forget things and then reach the point where they no longer manage to recognise even their family relatives and they need help even for the most simple daily activities. To this is added behavioural and mental symptoms such as depression, agitation and psychosis.

The memory deficit and the progressive compromising of the cerebral functions which are typical of Alzheimer's disease are due to a degeneration of the cholinergic neurons (which release acetylcholine). The brains of patients who have Alzheimer's disease are characterised by plaques made up of the accumulation of beta-amyloidal protein and the formation of clusters (neurofibrillar masses of tau protein).

C. Parkinson's Disease

Parkinson's disease[33] is the second most important neurodegenerative disorder after Alzheimer's disease. This is a neurological disease characterised clinically by the association of trembling when resting; bradykinesia (rare and slow movements); and rigidity, which can have the character of a toothed wheel and postural instability. Together with other types of Parkinson maladies, it strikes 0.3% of the population over the age of forty and 3% of people over the age ofsixty-five (250,000 individuals in Italy, 1-1.5 million people in the United States of America).[34] Its prevalence increases in an exponential way between the ages of 65 and 90. The average age for the onset of this disease is about 57 but in some cases it can begin in childhood or adolescence (youth Parkinson's disease).

Parkinson's disease is a disorder of many factors connected with age, in which genes and the environment contribute together to generate a risk.[35] It is not a specifically genetic disease but about 15% of the individuals with Parkinson's disease belong to a family in which there have been other cases of Parkinson's disease.[36]

At a pathological level,[37] Parkinson's disease appears to be connected to a loss of neurons that affects in a preferential way the dopaminergic neurons of the nigrostatial pathway, neurons that are located in the *sostanzia nera* (*locus niger*), a mesencephalic structure that is located under the thalamus and from which extensions reach the *striatum* (a structure that is a part of the basic nuclei). To this neuronal degeneration is added a deposit of proteins in the cytoplasm of the neurons, the Lewy bodies.[38] These hyaline and oenophile inclusions, which are rich in neurofilaments, constitute the histopathological stigmata of Parkinson's disease.

The first signs of this disease, which become steadily worse,[39] generally appear at the age of fifty. In 50%-80% of patients this disease has it onset in an insidious way with trembling when the hand is resting, a trembling which diminishes during movement and disappears during sleep, but which increased with emotion and tiredness. Subsequently, this trembling afflicts the hands, the arms and the legs to an increasing extent. In a large percentage (about 50%) of patients dementia can appear. Steadily during the later stages of the disease a memory deficit and behavioural disturbances can also be present. Lastly, forms of depression are often associated with Parkinson's disease.

Many risk factors and many protective factors have been advanced as regards Parkinson's disease, at times connected with theories regarding the possible mechanisms of this disease, but none have been identified with certain proof. However, studies have demonstrated a close link between Parkinson's disease and oxidative stress.

Parkinson's disease is characterised by its favourable response, at least at the beginning of its development, to substitutive treatment with a biochemical precursor of dopamine, L-Dopa or 'levodopa', which increases the level of dopamine in the brain.

At a therapeutic level, there is no cure for Parkinson's disease. The anticholinergics and surgery (for lesion of the pyramidal tract or the basic nuclei) were the only forms of treatment available until the arrival of levodopa in 1967, a drug which led to a real revolution in the therapeutic approach to this disease. At the end of the 1980s deep cerebral stimulation brought about a new therapeutic opening as regards this malady.

D. The Economic and Social Impact

The economic and social impact of neurodegenerative diseases and more in particular Alzheimer's disease and Parkinson's disease is devastating: diseases such as Alzheimer's last on average ten years, during which the autonomy of the patient diminishes, requiring growing commitments and costs on the part of his or her family. These patients are almost never hospitalised and over 75% of the treatment and care is provided by their families who live the daily drama of a health-care emergency which has still not been solved.[40] Their service for these patients amounts to a full-time job. Those people who care for patients with Alzheimer's disease within families often feel abandoned to themselves in a burdensome situation which is hopeless and very demanding. We should not, therefore, be surprised by the report of R. Schulz *et al.* (2003)[41] according to which 43% of people who care for people with Alzheimer's disease in families have a significant level of depression during the last months of the lives of these patients.

II. THE AGEING OF THE POPULATION AND NEURODEGENERATIVE DISEASES

The age of the individual is the most important factor in the occurrence of a neurodegenerative disease: these diseases generally begin during adulthood and they develop and get worse during the 'third' and 'fourth' ages of human beings. Their incidence on populations reflects, therefore, the proportional importance of the elderly part of the population compared to the population as a whole. Indeed, the proportion of people over the age of sixty in developed countries, and also in developing countries, has been increasing continuously compared to the rest of the population and it has been doing this for a number of decades. This ageing is due to two factors: a lowering of infant mortality and of death rates in adulthood, which have caused an increase in life expectancy at birth and during adulthood, on the one hand; and a decrease in birth rates, which is liked to the postponing of having children, and because of the spread of contraception and abortion in these countries, on the other.

A. The Increase in Life Expectancy

Human life expectancy at birth (LEB) which starting with the beginning of humanity took 300,000 generations to double, over the last hundred years, in less than ten generations, has increased twofold.[42] Global life expectancy in the world went from 64 in 1990 to 70 in 2011. Life expectancy at birth in the world increased 3-4 years every decade from 1970 to 2010. In 2011 life expectancy at birth was on average 72 for women and 68 for men.[43]

The increase in life expectancy at birth was first caused by the sharp diminution of infant mortality (more than 60%), in particular death caused by infections and malnutrition. However, the increase in life expectancy in developed countries has also been due in recent years to a lowering of death rates during adulthood:[44] in Europe in 1952 the probability of a person aged forty dying before the age of seventy was 39% in men and 27% in women. Between 1952 and 2006 this death rate fell 2.9% every decade in women to reach 12.5% in women and 23.6% in men.

This increase in life expectancy should not, however, lead us to have false expectations as regards a possible increase in human life spans in centuries to come. For example, the data on the increase in life spans in the Japanese, and more particularly Japanese women, indicate that only 4.3% of the cohorts born in 2000 will reach the age of a hundred. In the United States of America this figure becomes reduced to 2%.[45]

B. The Decrease in Birth Rates

The decrease in birth rates to be observed in developed countries is the result of a combination of factors, the most important being the decrease in the nuptial rate, the postponing of nuptials and the postponing of the first child, whether the couple is married or cohabits.

Over the last decades, and most especially in developed countries, this postponing of children has been facilitated by the possibility of having access to effective contraception or abortion. The decrease in the nuptial rate in Europe began to be manifested in Sweden and Denmark in 1965 and then extended to the rest of western Europe: Switzerland and Germany first, then England and Norway, and finally France and Italy. The result of this postponement of the first child by couples is that the number of births in developed countries has constantly decreased since the 1970s, a decrease that has been aggravated by extensive resort to contraception or to abortion where contraception has failed.

It is known that the indicator of fertility, that is to say the average number of live births for each woman, has to be slightly greater than the order of 2 in order to assure the maintenance of the population: in France this indicator was 2.93 in 1950, it then fell to 2.73 in 1960, to 2.43 in 1979, to 1.94 in 1980 and to 1.78 in 1990, before rising to 1.88 in 2000, to 1.92 in 2005, to 1.99 in 2009 and to about 2 in 2010.[46]

A similar decrease in birth rates has been witnessed in other European countries, but with varying levels:[47] Ireland: 3.21 in 1980, 2.05 in 2011; Iceland: 2.48 in 1980, 2.02 in 2011; United Kingdom: 1.90 in 1980, 1.96 in 2011; Sweden: 1.68 in 1980, 1.9 in 2011; Finland: 1.63 in 1980, 1.83 in 2011; Belgium: 1.68 in 1980, 1.81 in 2011; Holland: 1.6 in 1980, 1.76 in 2011; Denmark: 1.55 in 1980, 1.75 in 2011; Switzerland: 1.55 in 1980, 1.52 in 2011; Greece: 2,23 in 1980, 1.42 in 2011; Austria: 1.65 in 1980, 1.42 in 2011; Italy: 1.4 in 1980, 1.4 in 2011; Germany: 1.56 in 1980, 1.36 in 2011; Spain: 2.2 in 1980, 1.36 in 2011. In other non-European developed countries: Israel: 3.14 in 1980, 3.0 in 2011; New Zealand: 2.03 in 1980, 2.2 in 2011; the United States of America: 1.84 in 1980, 2.00 in 2011; Australia: 1.89 in 1980, 1.9 in 2011; Canada: 1.67 in 1980, 1.7 in 2011; Japan: 1.75 in 1980, 1.4 in 2011.

By way of comparison the figures for 2011 in other countries were as follows:[48] Niger: 7.03; Mali: 6.5; Somalia: 6.17; Uganda: 6.06; Burkina Faso: 6; Nigeria: 5.31; Ruanda: 4.71; Ivory Coast: 3.73; the Philippines: 3.10; Pakistan: 2.96; Egypt: 2.9; Algeria: 2.78; India: 2.55; Indonesia: 2.2; Venezuela: 2.37; Argentina: 2.27; Turkey: 2.10; Chile: 1.85; Brazil: 1.81; Russia: 1.61; China: 1.55; Poland: 1.32; the Ukraine: 1.29; Taiwan: 1.11; Singapore: 0.79.

From these indices it clearly emerges that countries such as China, Russia, Japan, Germany, Italy and Spain will have grave internal, industrial and economic problems in the near future when the lack of a young and active population will make itself painfully felt.

C. The Ageing of Populations

The increase in life expectancy and the lowering of fertility rates in the world had as their first result, in various countries, the so-called 'demographic transition',[49] that is to say the move from the traditional regime, that existed prior to the industrial revolution, in which fertility and mortality rates were high and were more or less balanced, to the 'modern' regime which developed in the countries of the industrial revolution starting in the eighteenth century in Europe, in which birth rates and mortality rates were low and balanced each other, with a lowered mortality rate and also a lowered birth rate. One should, therefore, find a balance, without the composition of the population concerned changing. In reality, this prospect of a 'zero population growth' has not taken place and matters have developed differently. A further decline in fertility rates has been witnessed and this has reached levels below the replacement level. This was something that appeared in the developed countries of northern Europe in the early 1970s because the decrease in fertility rates was accompanied in these countries by widespread changes in the attitudes and behaviour of people as regards sexuality, contraception, marriage and divorce. It is this second demographic transition that is the problem today inasmuch as it is responsible for the ageing of populations and the social, health-care and ethical consequences of this phenomenon.[50]

Today, the age band within populations made up of people over the age of sixty is increasing by 2% every year and thus much more quickly than the increase in the population in the world. It is calculated that this proportion of old people to the general population, which was 8% in 1950, 10% in 2000, and 11% in 2009, will reach 15% in 2025 and 21% in 2050.[51] This increase will certainly be more important in developed countries (with a proportion of people over the age sixty of 11.7 in 1950, 15.4 in 1975. 19.4 in 2000, 28.2 in 2025 and 33.5 in 2050) but it will also affect less developed countries (with a proportion of people over the age of sixty of 6.4 in 1950, 6.2 in 1975, 7.7 in 2000, 12.6 in 2025 and 19.3 in 2050).

In the year 2050 the number of people over the age of sixty will be greater than the number of young people for the first time in history.

In the year 2000 the world population had 600 million people over the age of sixty, that is to say three times the recorded number of fifty years previously. This number rose to 700 million in 2009 and to 810 million in 2011 and it is calculated that in the year 2050 there will be two billion such people, three times the recorded number of 2000.[52]

The countries that at the present time have the highest proportion of people over the age of sixty are (the figures are for the year 2011) in decreasing order: Japan (31%), Italy (27%), Germany (26%), Finland (25%), Sweden (25%), Bulgaria (25%), Greece (25%), Portugal (24%), Belgium (24%) and Croatia (24%).

The Pontifical Council for the Laity, in the introduction to its famous document of the year 2000 'The Dignity of Older People and their Mission in the Church and the World' referred in the following terms to the contemporary accelerated ageing of populations and its cause: 'The prolongation of average life expectancy, and the sometimes dramatic decrease in the birth rate, have given rise to an unprecedented demographic transition: the age pyramid that existed less than half a century ago has literally been turned upside down. The number of older people is constantly increasing, while that of the young is constantly decreasing. Starting out from the countries of the northern hemisphere in the 1960s, the phenomenon has now spread to those of the southern hemisphere, where the ageing process is even more rapid' (The Pontifical Council for the Laity, 'The Dignity of Older People and their Mission in the Church and the World', 1998).[53]

The increase in the 'passive' part of the population – elderly people – while the 'active' part on which the economy rests constantly decreases has created a 'silent revolution' which goes well beyond demographic data and raises grave problems of an economic, social and cultural character.[54] This imbalance partly explains the 'marginalisation' or rather 'social euthanasia' that is suffered by many elderly people today. The elderly person is thus 'relegated' to a 'loneliness which is a kind of social death' (John Paul II, 'Letter to the President of the Second World Assembly on Ageing', 3 April 2002).[55]

D. The Increase in Disability and the Increase in Life Spans

This ageing of populations could be seen in positive terms if human life could be extended without the health of individuals being affected. But in reality such is not the case. Indeed, the extension of life spans has been matched by an increase in disability.[56] Whereas man can live longer, this does not mean that he benefits from more years of good health. From 1999 to 2010 life expectancy for men increased by 4.7 years and for women by 5.1 years, but the years with good health that were gained were only 3.9 years for men and 4 years for women.

Healthy life expectancy (HALE) has increased more slowly than life expectancy itself: from 1990 to 2010 HALE increased by 5 years or more in 48 countries for men and in 43 countries for women; however HALE decreased in 22 countries for men and in 11 countries for women. HALE at birth rose from 54.8 years in 1990 to 59 years in 2010 for men and from 58.7 years in 1990 t5o 63.3 years in 2010 for women.[57]

The increase in life spans has thus led to a growth in disability in these years of old age with anxiety, muscular and bone pains, the loss of vision and of hearing. and a notable increase in the incidence and prevalence of neurodegenerative diseases.

E. The 'Silent Epidemic' of Alzheimer's Disease and Parkinson's Disease as a Consequence of the Ageing of Populations

This increase in neurodegenerative diseases in populations concerns in particular the two diseases directly connected with the ageing of the human brain, that is to say Alzheimer's disease and Parkinson's disease. There are already about 34 million people in the world who suffer from the dementia of Alzheimer's disease;[58] it is calculated that 7.7. million new cases of dementia exist each year. that is to say one new case every 4 seconds;[59] and it is estimated that the number of cases of dementia in the world will reach 65.7 million in the year 2030 and 115.4 million in the year 2050. We are thus in the presence of an authentic 'silent epidemic' of a gravity to be compared to AIDS at its beginning which threatens the balance of public health and raises grave human and social problems.

III. THE TEMPTATION: A REDUCTION IN HEALTH AND SOCIAL CARE AND EUTHANASIA

The burden that neurodegenerative diseases constitute today for public health and the institutions of social solidarity, in various countries, and the prospect of a constant increase in the future of the number of individuals who are affected by these diseases – principally Alzheimer's disease and Parkinson's disease – naturally leads the people who are responsible for these services, and those who assure the acceptance, and social, material and care for individuals with these diseases, to decide which responses can be given in an effective way to this neurodegenerative 'epidemic'.

There are two kinds of responses: the proposal to reduce the access of people afflicted with neurodegenerative diseases, and in particular Alzheimer's disease and Parkinson's disease, to the existing health-care system, whether public or private, on the one hand; and the proposal to accelerate the natural process that leads to the disappearance of these people through euthanasia, assisted suicide or terminal palliative sedation, on the other.

A. The Proposal of Rationing

There is no doubt that the ageing of populations in the world raises serious problems for health-care institutions because people over the age of sixty-five turn to health care much more frequently than young people do. For example, in the United States of America people over the age of sixty-five make up about 13% of the population but they utilise 36% of health-care resources. The average expenditure on health care for elderly people is $11,089 a year but it is only $3,352 a year for people who are under that age limit and belong to the 19-64 age band.[60] The disproportionate cost of health care for elderly people makes these people an obvious target from the perspective of a rationing of health care which became obligatory for economic reasons. The proposal in this way to limit this rationing to the category of people afflicted by neurodegenerative diseases might appear acceptable to the extent that these people constitute a notable burden for society without offering much in exchange.

The efforts that have been made in the past to limit the access of elderly people to health care have, however, encountered strong resistance, above all from the largest international institutions, such as the European Union (2007, article 21), the World Health Organisation (2002), and the United Nations (1948, preamble). These organisations have rejected every form of discrimination based upon the age of people and have emphasised the equality of rights to access to health care for everyone, including elderly people. This resistance is based upon human rights, and specifically upon the article of the Declaration which stresses the equality of human rights 'in dignity and rights'. The proposal to limit restriction to access to health care to the specific group of people afflicted by neurodegenerative diseases can only be rejected by these institutions because it would be an unjust discrimination against, and stigmatisation of, a human group and contrary to article 11 of the Universal Declaration on Bioethics and Human Rights of UNESCO.

Even if an international or national institution were to accept a restriction in access to health care for people with dementia or people over the age of 65, the universally accepted bioethics of 'principles'[61] could only strongly oppose in the name of justice such a proposal which is not only discriminatory in character but which also does not take into account in the least the notable past economic and human contribution to society of people who are currently elderly.

To by-pass this resistance Norman Daniels argued in his book *Just Health* (2008) in favour of the 'lifespan account', according to which we should see our lives as a whole rather than from the perspective of a particular moment in time. In these conditions, it would appear prudent for us to prefer a health programme that distributed less services during old age in exchange for more services before old age. From this point of view, the rationing of health care according to age would be compatible with the principle of equality: in this approach, everyone would be treated the same over time, preferring only to have more resources during the active period of life in exchange for less resources later.

Nancy S. Jecker replied to Norman Daniels by asserting that the proposal of a 'lifespan account' is not right because one cannot be at one and the same time both young and elderly, and therefore cannot be at the time of the acceptance of the proposal both young and old. Nancy S. Jecker proposes another approach, that of 'capability',[62] according to which there is a normal duration of life for man in which an individual is entitled to maintain his or her capacities, which is the basis of his or her dignity. Beyond the threshold that corresponds to the limit of a normal duration of life there is said to be no longer the right to health care that assures the conservation of life during the normal duration of life. This approach of Jecker does not seem to be more than ethical than the approach of Daniels: how can one justify at an ethical level a policy as regards health care which, after all the efforts made to conserve the life of a person until reaching the 'threshold' after a 'duration of life' held to be normal, would abandon that person, denying him or her the resources that are necessary to prolong his or her life?

In reality, as L. Capitaine and G. Pennings (2013) demonstrate,[63] the idea of a rationing of health care based upon the age of the individual involved, however this may be presented, is not a suitable response to the crisis of the costs of health care. The error in the proposal of rationing is to think that the problem comes from the ageing of the population because, in fact, it actually comes from the technology of medical science itself which is the principal factor responsible for the increase in costs in the health-care field. It is the development of technology that is responsible for 50% of the annual increase in health-care expenditure. One is dealing, therefore, with abandoning concern about ageing and paying attention to medical technology and its increasingly growing economic demands. From this new perspective, the commitment to taking measures to contain the costs of health care becomes an authentic challenge: if we really want to contain the costs of health care we must ration the technology involved itself and this as regards all ages, applying this rationing to methods that are not of vital concern. Such a rationing will probably be less popular and less accepted than rationing applied only to elderly people, in particular as regards that part of the population that is active and holds power. But such a fair rationing, bearing upon the secondary and not vital aspects of medicine, appears to be the price to pay to have a health-care system that is at one and the same time both ethical and viable.

B. The Temptation of Euthanasia

Although the proposal to engage in rationing has in itself an argument that is valid – that is to say not only the need to contain expenditure in the field of health care but also the need to meet the problematic situation created by the ageing of the population – such is not the case as regards the acts of euthanasia that could be engaged in in relation to people with Alzheimer's disease or Parkinson's disease. Whereas the proposal to have a policy of rationing could have some positive effects as regards the common good in establishing a balance with respect to public health, euthanasia has no benefit for society or a human group. The only benefit that could come from this practice would be satisfaction of an ideological character involving the feeling that one had thus contributed to ending a human life that is assessed as not 'worthy' and a 'burden for society'. But this assumes a perversion of the conscience which cannot be seen as a good. The only legal 'justification' for such an act would be if the interested party had requested it both directly if still conscious and capable of responsible decisions and before the loss of his or her autonomy, for example through the contents of prior directives.

In the case of Alzheimer's disease it is an exceptional event for the patient in his or her state of cognitive deterioration to be able to make a formal request for euthanasia. Furthermore, such a person is not about to die and can, indeed, enjoy excellent health. Bioethics totally prohibits such euthanasia because it is carried out on a person who is not competent and who, furthermore, does not manage to express himself or herself and to provide valid consent. However, the law in Holland, Belgium and Luxembourg authorises the practice of euthanasia on people who suffer from severe dementia and in the case of people who have foreseen their decline and have requested through prior directives to receive euthanasia when they have lost the ability to ask for it directly in the future. C. Gastmans and J. de Lepeleire (2010),[64] when studying this proposal with great objectivity, concluded that a decision to proceed with euthanasia in the case of dementia in the name of the 'dignity' of the patient does not in fact respect this dignity because the patient can never lose his or her dignity whatever his or her pathology and his or her level of consciousness. They added that the argument of 'poor quality of life' which is also invoked to justify euthanasia in cases of dementia is not valid because the 'quality of life' of people with dementia can be perfectly safeguarded through palliative care. They concluded that if the autonomy of an individual deserves profound respect, such autonomy cannot have an absolute dominion over his or her life but, rather, must be understood within the wider framework of fundamental ethical values.

In the case of Parkinson's disease, when the patient has all of his or her cognitive capacities, he or she suffers at the sight of seeing his or her activities increasingly reduced and can become depressed because of the consequence of the worsening of his or her illness. If, in addition to this situation, this patient does not have the support of family relatives or visitors who support him or her morally and comfort him or her spiritually, it is in fact possible that he or she will express a wish to end his or her own life. But if someone intervenes in this situation of dereliction, anxiety and despair to bring to the person involved an attentive human presence that is respectful of his or her dignity, and is beneficial and compassionate, this request for euthanasia is generally abandoned by the individual concerned. To end the life of this person who is suffering morally rather than coming towards his or her suffering in a helpful spirit is a solution involving what is easy, a discharge. It is true that some bioethicists are in favour of a strict application of the principle of autonomy in this framework of decisions of the patient but the following question can be posed: would it not be better, humanly and spiritually, to go beyond this strict principle of 'doing good-not doing bad' to achieve the principle which is a equally human and noble of 'benevolence'?

In the case of a very advanced form of Parkinson's disease, where vital support is needed, the question of moving for the patient from care of a therapeutic character to care of a palliative nature can be presented to the patient and discussed with him or her. As the patient rarely suffers and rarely needs positive respiration, rarely is the question raised of a palliative sedation that could be terminal. Indeed, every time that this is possible, it is preferable that the patient goes back to his or her own home to die in serenity and peace, accompanied and supported by his family relatives.

Although some bioethicists[65] have declared that they are in favour of euthanasia, as practised in Holland, even in cases of 'existential suffering' without actual suffering or malaise caused by incapacitating pathologies, one should emphasise against them, at the moment, that natural moral law, the commandments of God, universal human rights (which exclude the 'right to die') and the Magisterium of the Church all clearly condemn resort to euthanasia, assisted suicide or terminal palliative sedation for the purposes of euthanasia. The Blessed John Paul II went beyond these solemn condemnations and encouraged people with Alzheimer's disease or Parkinson's disease to live their lives until their natural end and to have a positive assessment of this period of trial (*Salvifici Doloris*, n. 19). The commandment of love, strongly illustrated by the parable of the Good Samaritan, makes it the duty of Christians to accompany these patients suffering from Alzheimer's disease or Parkinson's disease, bringing to them serenity and hope.

IV. THE RIGHT RESPONSE TO ADDRESSING THE CHALLENGE OF NEURODEGENERATIVE DISEASES TOMORROW

Although conferring death on these people with Alzheimer's disease or Parkinson's disease is not a worthy and human solution, and although medical care must be proposed to these people without rationing or limits, the most important questions remain: what response must health-care authorities give to the massive increase in neurodegenerative diseases? How should they behave in order to be just, not discriminate against elderly patients with a dementia or Parkinson's disease, and at the same time make savings as regards the available resources so that nobody suffers because of the new health-care situation?

The impact that Alzheimer's disease and Parkinson's disease already have on the economies of developed countries is notable and this impact can only increase in the years to come. This situation will be further exacerbated by the fact that the funding of health and social services will face increasing restrictions in the years to come when we take into account the current economic crisis. Health-care services are thus rightly worried about this envisaged wave of incapacitating diseases which run the risk of destabilising the working of state health services, meaning that it will become increasingly difficult for people to obtain the correct treatment.

In addition, it has been demonstrated that Alzheimer's disease and other dementias are responsible for high levels of excess in the costs of managed care organisations. H. Fillit *et al.* (New York) (2002),[66] starting with a group of 1,366 patients with Alzheimer's disease, calculated that the annual cost for these patients was $3,805 greater than the cost for people without Alzheimer's disease and that this caused an excess in costs of $5 million for the managed care organisation studied (Medicare). R. Frytak *et al.* (2008)[67] reported that patients with Alzheimer's disease have health care costs and a risk of secondary acute events that is higher than that of other members of these organisations. These authors found that the health costs per patient were $1,418 higher in Alzheimer's disease than in other patients. Thus, both given the envisaged increase in the number of people neurodegenerative diseases and in order to reduce excessive health-care expenditure on these people, at the present time the concern is to reduce the costs that neurodegenerative diseases impose on health-care services and on society. In recent years a manifestation of this concern has been the increase in the number of economic studies on these diseases.[68] The question that all these studies pose is the following: how can one optimise state health-care service to meet the needs of patients with neurodegenerative diseases without reducing care for younger patients with other kinds of illnesses and without altering the quality of life of patients with neurodegenerative diseases?

A. Taking Greater Care of People with Neurodegenerative Diseases

The observation that has just been made about the higher health-care costs of patients with AD (Alzheimer's disease) or PD (Parkinson's disease) could lead us to measures involving a reduction in the care offered to patients who suffer from Alzheimer's disease or Parkinson's disease given that such patients cost more to society and absorb resources that are taken away from active people. A more careful examination of the realities of the situation of these patients demonstrates that such a reduction would be a grave error. Indeed, if patients with Alzheimer's disease or Parkinson's disease cost more to managed care organisations this is because they are more or less abandoned to themselves, without medical surveillance, and develop grave morbose conditions which cost more to be treated than if attentive medical surveillance had foreseen their appearance. J. W. Hill *et al.* (New York)(2002)[69] observed the situation of 3,934 patients with Alzheimer's disease or dementia in old age and found that the annual costs for these patients were $4,134 more than the costs for people without Alzheimer's disease. This meant a supplementary cost for Medicare of $16 million. These excess costs were due to the treatment of grave morbose affections that could have been prevented if the people with Alzheimer's disease had been followed correctly from a health-care point of view and their complications prevented.

B. Identifying the Most Effective Therapies as Regards Costs

1. Assessing Costs

The first question that these studies pose is that of the assessment of costs in order to direct treatment towards the most effective forms in terms on costs. The problem is that these costs vary a great deal according to the conditions of care and the patients themselves. For example, L. J. Findley (2007)[70] reported that in the United Kingdom the total cost for Parkinson's disease was between £449 million and £3.3 billion. L.J. Findley observed on this subject that the most important part of direct costs came from medical care and admission to specialised homes, whereas the costs in medical products constituted a more limited part of overall costs. The indirect costs were also important. S. von Campenhausen *et al.* (2011)[71], in a study on the costs of Parkinson's disease carried out on 486 patients in six different countries in Europe over a period of six months, reported that there was a great variation in these costs from one patient to another. The total average cost per patient was from 2,620 euros to 9,820 euros. Direct costs made up 60% to 70% of the total costs and indirect costs made up about 30% to 40% of the total costs. The great variation between the costs that were reported was a result of the differences between the health-care systems of the countries involved, the local economic conditions, the frequency in the use of resources, and the differences between the prices involved from one country to another.

2. Identifying the Most Effective Forms of Treatment in Terms of Cost

To reduce the costs connected with care in terms of medical products or surgical operations, the attempt has been made to determine what is the most effective kind of treatment in relation to its cost. As regards Parkinson's disease, the assessment is that the use of levodopa, in habitual combination with a dopa-carboxy-lyases inhibitor and an enzyme inhibitor (COMT) which breaks down dopamine, the agonists of dopamine and the monoamine oxidosis inhibitors (MAO-B), and deep cerebral stimulation, is efficient in terms of costs within the framework of a suitable therapeutic decision.[72] However, such an assessment of efficiency depends a great deal upon the cost of the medical products used and the method of assessment employed as regards their effects.

C. Preventing the Deterioration of Neurodegenerative Diseases

In addition to the calculation as regards the efficacy of forms of treatment one should take account of another factor in terms of the reduction of costs as regards neurodegenerative diseases, namely the level of development of the disease. The cost of the management of these diseases, indeed, increases notably as these diseases advance in their development and become worse, whether one is dealing with Alzheimer's disease or Parkinson's disease. As regards Alzheimer's disease, J. Leon and P.J. Neumann (1999)[73] indicated an annual total cost that went from $14,904 for minor forms of Alzheimer's disease to $19,272 for moderate forms and on to $25,860 for the most severe forms. J.P. Deese *et al.* (2011)[74] calculated that in the case of a German patient with Alzheimer's disease the total annual cost was 13,080 euros per patient. The most important component of this cost was health care which made up about 43% of the total costs. The indirect costs made up about 18% of total costs and corresponded for the most part to reduction in labour time for those who cared for patients and looked after them. The more Parkinson's disease advances, diminishing the functionality of the individual, the more these indirect costs increase. In order to reduce the costs of the management of Alzheimer's disease, it is not therefore sufficient to have resort to less expensive but effective treatment. One must also prevent the worsening of the disease and slow down its advance through a policy that is not limited to less expensive treatment but which provides also prevention of the illness. Such a policy of prevention of the worsening of the disease is recommended in particular for patients with Alzheimer's disease. Such prevention can take the form of using pharmacological help such as an acetyl cholinesterase inhibitor (doe example donepezil) which slows down cognitive decline in Alzheimer's disease.[75] But it also takes the form, and perhaps above all else, of greater attention being paid to the patient as regards his or her behaviour, lifestyle and spiritual wellbeing.

D. Drawing upon the Help of Families or Arranging more Suitable Environments for the Accommodation of Patients

There is a third point to consider as regards reducing the costs of the management of neurodegenerative diseases without reducing the quality of care that is provided. This point is connected with the material, affective and spiritual conditions in which a patient finds himself or herself and which greatly influence the efficacy of treatment and also its cost. By way of example, D.P. Rice *et al.* (San Francisco) (2001)[76] reported an average cost of $27,672 per patient per year in Alzheimer's patients and other dementias. The individual costs were from $10,400 to $34,517 per patient. In contrast with these rather high costs, J .P. Reese *et al.* (2011)[77] studied a group of people with Alzheimer's disease in Portugal and calculated that the direct costs for people with Parkinson's disease was 2,717 euros per patient and for a period of six months (544 euros for the medical products, 690 euros hospitalisations), whereas the indirect cost was 850 euros. The patients themselves contributed 12% of the direct costs. Most of the economic assistance for the patients came from their families. The authors of this report observed that these costs were without doubt inferior to those in other developed countries for the same kind of illness.

This example clearly demonstrates the help that the family can give to the medical management of Alzheimer's disease or Parkinson's disease when the family still exists as the 'heart of the civilisation of love' which remains faithful to its vocation and which lives to the full the value of strong solidarity in the mutual communion of the people who make it up.[78]

It is true that such a model of the family is becoming increasingly rare nowadays and that often people with Alzheimer's disease or Parkinson's disease are alone, disorientated, and without a hearth to welcome them and keep their spirits lively. But it is not impossible in such conditions to offer these people a place for living that is better in human terms than the anonymous beds of some institute for elderly people thought of a century ago in line with the model of prisons or psychiatric hospitals.

S. Drapier *et al.* (2005)[79] observe that the assessment of efficacy as regards the costs of a given therapy habitually and solely concerns the physical and objective aspects of such a therapy without going into the question of the 'quality of life' itself of the individual concerned. For example it is true that sub-thalamic stimulation allows a reduction of the physical ill-effects of medical treatment with levodopa. But the quality of life of patients also depends on other factors which are not physical in character but which are connected with their conditions of life: according to Drapier *et al.* the social support that they meet with, their ability to communicate, and their feelings of wellbeing at an emotional level.[80] These human needs can be met without great difficulty when people stay with their families, within their usual framework of living, with familiar objects near to hand and in sight. When there is no family, or when the family relatives are far away or cannot help, it is much more difficult to recreate artificially for people a framework of life that is in line with their tastes and habits. But this is not something that is impossible. In doing this one brakes the implacable advance of the disease and the cost to the institution is largely covered by the economic savings that are obtained in this way.

It is obvious from these data that strategies of governments must be established in order to minimise the impact of the increase in these diseases while maintaining a satisfactory quality of life for these patients. One is dealing, therefore, with optimising the use of resources in order to address the situation in the years to come.

E. Taking into Account the 'Quality of Life' of Individuals at a Mental and Spiritual Level

This reflection on the importance of the family in preventing a worsening of neurodegenerative diseases and also on the importance of wellbeing at a relational, affective and spiritual level, leads us to a practical and immediate conclusion: one should not limit oneself in the restrictions envisaged to the care offered to patients with Alzheimer's disease or Parkinson's disease to a simple cost/benefit assessment, that is to say an assessment in purely economic terms. One should also take into account the conditions of life of the individuals concerned[81] and the fact that the 'quality of life' of these individuals does not depend only on their physical wellbeing: it is very much conditioned by their state of mind. To this end, efforts should be made to prevent a worsening of these diseases through the paying of greater attention to the conditions of life of such patients, to the maintenance of their physical capacities and to the exercise of their mental faculties.[82] Families should be involved in this effort that is directed towards at welcoming and supporting elderly people with dementia or Parkinson's disease.

Policies of an epidemiological character and ones in line with ethics, based upon surveillance, prevention, treatment and solidarity are the most just and suitable response in opposition to the temptation of 'selective rationing' or euthanasia in relation to elderly people with neurodegenerative diseases. They respect elderly people afflicted with dementia or who are unable to move because of Parkinson's disease. They respect and they help. If such policies were approved at a political level and then implemented we would demonstrate that our civilisation is still capable of generosity and solidarity.

CONCLUSION

In the responses that health-care authorities can give to counter the almost exponential increase in neurodegenerative diseases there are three types of measures which can be identified according to the immediacy or otherwise of their purpose.

In an immediate sense, one is dealing with adapting the instruments of health-care and social assistance that are available to the specific situations of people afflicted with neurodegenerative diseases and who often find themselves socially isolated and not infrequently also abandoned to themselves, at least at the level of medical care. Many of these people do not have the economic resources to be placed in specialised homes. In such a situation the family has an essential role to perform as regards care and support for its sick member. But the family must be supported, sustained and encouraged in this mission, However, it is no rare occurrence today to encounter elderly people who do not have a family or at least do not have family relatives who are nearby, and society, moved by the duty to engage in solidarity, must be able to develop places of admission that are suitable for these people who are especially vulnerable, so as to prevent a worsening of their illnesses, especially in the case of dementia.

In the short term a policy of prevention as regards neurodegenerative diseases must be undertaken through the education of the population in relation to them and to the factors which, written into lifestyles, facilitate the onset of a neurodegenerative disease, in particular Alzheimer's disease. It appears that effective prevention could prevent almost a half of the cases of Alzheimer's disease.

In the long term there is the question of going to the roots of the evil and countering the ageing of populations. The only remedy by which to rebalance the current demographic imbalance is to practise policies that foster births, that is to say, in practical terms, policies that favour the family.

Beyond these necessary curative and preventive provisions as regards neurodegenerative diseases with reference to the ageing of populations, there is the need for an authentic cultural change that would allow a rediscovery of the value of elderly people in society, even when they suffer from disabilities. In the place of the 'social euthanasia' which is currently practised in developed countries, one needs to rediscover respect for elderly people, the basis of authentic solidarity towards them, together with a sense of the equality of everyone, whatever their age and their state of health.

The Blessed John Paul II invited us to have such a joyful respect when he wrote his 'Letter to the Elderly': '"Rise in the presence of one with grey hair; honour the person of the older man" (*Lev* 19:32). Honouring older people involves a threefold duty: welcoming them, helping them and making good use of their qualities. In many places this happens almost spontaneously, as the result of long-standing custom. Elsewhere, and especially in the more economically advanced nations, there needs to be a reversal of the current trend, to ensure that elderly people can grow old with dignity, without having to fear that they will end up no longer counting for anything. There must be a growing conviction that a fully human civilization shows respect and love for the elderly, so that despite their diminishing strength they feel a vital part of society'

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2. The Sick Elderly Person in the Context of Migration

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Today, more than 215 million people, 3% of the world's population, live outside their country of origin, mostly in search of better working opportunities and livelihoods. Around 8% of these international migrants are asylum seekers and refugees and live predominantly in developing countries. Migration has many faces, from the highly qualified CEO working abroad to the migrant construction worker, from the refugee in an overcrowded camp to the victim of trafficking, from the undocumented migrant seeking a better life to the internally displaced person. Additionally, migration movements have become more 'mixed', meaning that migrants with different legal status and protection needs are migrating next to each other. In my paper I will refer to the Final Report on health monitoring of migrants in Switzerland,[1] prepared in 2011 for the Swiss Federal Agencies, as well to the analysis developed by the International Catholic Migration Commission.

The Swiss Federal Office of Public Health commissioned a monitoring report on the health of the immigrant population in Switzerland, which, for the very first time, collected representative data for defined health determinants from selected groups. As of 2009, a total number of 1,714,000 foreign nationals were registered as residing in Switzerland, accounting for 22.0% of total population, which is – in practice – the highest net foreign population in Europe and one of the highest in the world. The research assignment aimed to answer the following three main questions: what are the principal health differences between the indigenous population and people with a migrant background in Switzerland as regards their health status, their health behaviour, their health skills and their access to the health system? Which groups within the migrant community in Switzerland are most vulnerable in health terms? And what are the main determinants of the detected health differences and what impact do they have?

The results indicate that currently it is mainly in people with a comparatively good psychological and physical condition from the study countries that set out to migrate. However, the health status of older male and female migrants residing in Switzerland, who have generally been in Switzerland for quite a long time, is generally worse than that of Swiss men and women of the same age. Women migrants also generally score worse in terms of their health status than men. The older the migrant population, the greater the difference between men and women. Such differences are hardly, or less, apparent in the indigenous population.

Migrants visit a doctor specialist less often than the indigenous population does. However, visits to a general practitioner are more common among migrants than in the indigenous population. As regards the use of the emergency services and hospital outpatient facilities and/or outpatient clinics, the results show that some of the migrant groups under study call on them more often than Swiss citizens. These differences are relatively small, though. Female and male migrants have a lower rate of medical check-ups than indigenous Swiss. As a rule, a lower rate of use of outpatient health services for preventive measures, like vaccinations medical check-ups, advice, or of outpatient check-ups and care for chronic illnesses, lead to a need for expensive inpatient treatment later on. Female and male migrants consume significantly less alcohol than Swiss citizens, but they also eat less fruit and vegetables and do substantially less physical exercise. Furthermore, female and male migrants are far more frequently severely overweight. There appears to be considerable room for improvement in the promotion of positive health behaviour. Tobacco consumption is far higher among men with a migrant background than it is among Swiss men; for women, the differences between migrants and Swiss citizens are less consistent. Although choosing a doctor and communicating with him or her poses comparatively few problems to respondents with a migrant background, medical recommendations and advice are not often challenged. However, between 15% and 45% of respondents, depending on the migrant group, often cannot explain their concerns to the doctor or do not understand the doctor's advice well enough.

There are differences between people granted asylum and indigenous Swiss with respect to seeing a general practitioner in particular: people who have been granted asylum do this more often. As far as the duration of hospital stays is concerned, Swiss men and women tend to spend longer in hospital than people granted asylum. There are significant differences in the use the indigenous population and the asylum population make of accident and emergency departments, outpatients departments and outpatient clinics. There is little difference between the two populations in terms of the proportion of people who had visited such an institution at all in the past year. Overall, however, people granted asylum made a significantly higher number of visits to one of these institutions than the Swiss population. In terms of nutrition and physical exercise, it is apparent that the proportion of individuals who hardly ever eat fruit and vegetables and are physically inactive is higher within the asylum population than among Swiss citizens. There are clear differences with Swiss men and women in terms of alcohol and tobacco consumption. Alcohol is consumed far less frequently by people granted asylum than by Swiss citizens. The proportion of teetotallers is especially high.

The health skills of the asylum respondents is on the whole somewhat lower than for the other migrant groups, particularly in terms of assessing symptoms and understanding the health system. Compared to other migrant groups, the asylum population is relatively bad at evaluating whether symptoms require a visit to a doctor. While this is mainly a consequence of a lack of knowledge about physical complaints, the asylum population systematically underestimates psychological symptoms. People seldom consider it necessary to see a doctor for psychological complaints, even when this is medically advisable. There are huge problems of understanding between asylum respondents and the doctors treating them. Only a little more than a third of Somalis and a quarter of people from Sri Lanka can make themselves adequately understood to a doctor; the rest of the asylum population cannot do this at all or only occasionally. These people have similar trouble understanding a doctor's instructions or questions adequately.

The monitoring reveals that younger male and female migrants who have only just immigrated to Switzerland are somewhat healthier than the indigenous population, and that older female and male migrants, and those that have been in Switzerland for longer, are somewhat less healthy. Within the migrant population, women score somewhat worse than men in terms of their health status. No assessment is possible as to whether the results described above are due to an immigration or cohort effect. It thus remains an open question whether the health of the older and somewhat more ill migrants, in comparison with the indigenous population, was already worse when they arrived in Switzerland or whether they immigrated to Switzerland with above-average physical and psychological health. Closer analysis seeks to elucidate the differences in various health indicators between people with a migrant background and the indigenous population. This enables us partially to explain these differences by the migrants' lower level of education, inadequate language skills, experiences of discrimination in Switzerland, and experiences of political persecution and violence in their countries of origin. In the case of migrants who have been in Switzerland for longer, other factors apply that might have played a role in the past, both in Switzerland and in the country of origin. Additionally, migrants have to cope with multiple responsibilities: family, work, integration. What is more, they receive less support from older generations than the indigenous population and are more likely to face conflicts with the younger generation. However, it is also possible that younger, healthier age groups return to their homeland after a certain length of time, whereas those with health problems stay in Switzerland due to the better healthcare.

One of the main problems of the elderly migrants is self-reliance and self-sufficiency. All people need help at some point. Help is something normal, a matter of course. Though there are a number of benefits to an ageing society – leading longer and healthier lives, for example – it poses a lot of challenges, too. After all, a higher number of older people can no longer be sufficiently supported by a declining number of younger people. Supporting services – home care, family support and domestic services – can relieve not only the burden of the elderly themselves but also that of their relatives. They can also help the elderly to live an autonomous life, in their own homes. And elderly migrants are in a special situation, they are very sensitive, very often without a family, relatives or community support.

In Germany, for example, home care is mainly funded by the public sector. However, this form of financing – in its current shape – certainly has its limits. In European terms, the German number of care-dependent people is average. But the German care system has a comparatively small number of home care staff, which means an unfavourable ratio of older care-dependent people to such staff. The lack of skilled workers, the huge staff turnover and the short period of time home care nurses pursue their profession are phenomena that reveal the problems inherent in care services. There is a very huge number of potential staff for family support and domestic services. However, these service providers often render their services in the black economy. The aim thus has to be to integrate these people into the formal labour market, which could also trigger professionalisation and better qualification.

The form of elderly care that is provided varies greatly between countries and is changing rapidly. It has been observed that the global elderly consume the most health expenditure of any other age group, an observation that shows worldwide eldercare may be very similar. We must also take into account an increasingly large proportion of global elderly, especially in developing nations, as continued pressure is put on limiting fertility and decreasing family size. Traditionally, elderly care has been the responsibility of family members and has been provided within the extended family home. However, this model is almost impossible to achieve for most elderly migrants. The reasons for this change include decreasing family size, the greater life expectancy of elderly people, the geographical dispersion of families, and the high financial costs of institutional treatment.

A high social and economic demand for domestic care-giving services for elderly people has generated a rapid development of this sector. An overwhelming majority of caregivers are migrants, because of the specific character of this low-income sector, and today in Europe a growing number of them are women of Eastern European origins. A significant part of the care-giving sector is dominated by private companies; job placement is in practice monopolized by private, small recruitment agencies. The race for profit and the lack of responsibility of private agents causes negative, sometimes even criminal, situations: recruitment of staff without skills, qualifications and professional experience; very low standards of delivered services; and illegal labour or work in conditions inconsistent with minimum standards. This results in pathologies like violations of the safety and health of elderly patients and the exploitation of migrant caregivers. The specificity of domestic work makes the problem difficult to solve. The dynamic demographical changes in Europe, ageing societies, especially in Eastern Europe, will additionally intensify this phenomenon.

The International Catholic Migration Commission has been working in the field of migration for the past sixty years. As a Church commission it has helped more than one million refugees to start a new life in a third country. It promotes resettlement as a vital solution for refugees around the world who hope to regain a sense of long term normalcy in their lives. It advocates for the protection of migrant workers and their families and works with governments to reduce vulnerabilities and to open legal doors for migrant workers, and it contributes to restoring community life. It remains committed to all uprooted people regardless of their faith, race, ethnicity or nationality. The International Catholic Migration Commission recently developed the first pilot programmes in Eastern Europe, in partnerships with specialized local entities that are focused on selection, recruitment, orientation and vocational trainings for domestic caregivers for elderly people. Action is implemented in cooperation with local authorities and regional public employment administrations. Vocational trainings focus especially on the ethical standards of the profession and are ended with tests confirming necessary skills. After the first phase in countries of origin, the second phase of vocational training with final certification exams of professional skills takes place in the countries of residence of migrants. Finally, the caregivers are transferred to a professional service in regional caregiving institutions of the social economy sector in Eastern Europe, with circular, temporary 2-3 months contracts by regional domestic care operators in Western Europe. Shuttle labour in Eastern and Western Europe in the care-giving sector, with timeframes adapted to individuals and a general rule of circular labour migration, action is implemented in coordination with the local authorities in charge of the care-giving services and social regional operators.

This innovative project of the International Catholic Migration Commission includes also the transfer of Western developed solutions in the field of the solidarity economy, which can be adapted in Eastern Europe, such as the Swiss Spitex system and the *cheque-emlpoi* social solidarity economy solutions for domestic workers with local authorities.

Our project also provides an information campaign, with preventive measures – the social importance of care-giving for elderly people, requirements needed to provide caregiving services, but also the threats and dangers connected with illegal work or unfair recruitment practices resulting in the exploitation, mistreatment or trafficking of people. This information campaign will be implemented by the ICMC with the use of thematic websites and social media on Internet, as well as publications. In Switzerland the campaign will also be targeted at irregular domestic workers from Eastern Europe, especially the potential victims of exploitation or trafficking, offering support in changing current status or voluntary return. Information will be distributed through the use of consular services.

The project of the International Catholic Migration Commission should bring results in three fields: the building of quality ethical and professional standards in the sector of care-giving for elderly people in Eastern Europe; the elimination or reduction of illegal practices and the prevention of the exploitation and trafficking of domestic workers recruited in Eastern Europe; and the strengthening of development cooperation with Eastern European countries through technical assistance, circular labour migration, and the sharing and promotion of social-economy solutions in the field of care-giving at the level of local authorities and regions.

A combination of partnerships with local authorities, regional public employment services and care-giving institutions of the solidarity economy generates a better synergy of our actions and a more pragmatic and functional use of infrastructures and resources. ■

Notes

[1] Second Health Monitoring on the migrant population in Switzerland (GMM II). The National Migration and Public Health Programme (2008-13) included measures and schemes for prevention, healthcare, education and research. The programme aimed to contribute to a reduction in health discrimination against people with a migrant background in Switzerland and to improve conditions so that they can enjoy the same opportunities to reach their health potential as indigenous Swiss. As part of its research, the Federal Office of Public Health (FOPH) commissioned a monitoring report on the health of the immigrant population (GMM) in Switzerland, which in 2004, for the very first time, collected representative data about the health of selected groups. The FOPH later decided to commission a second health survey for people with migrant backgrounds (GMM II) in order to obtain a more detailed set of data.

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3. The Epidemiological Situation in Italy and Contemporary and Future Strategies of Health-Care Policy for a Suitable Management of Neurodegenerative Pathologies

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Italy

Definition

Neurodegenerative pathologies make up the great majority of the 600 neurological pathologies now known to medical science and are characterised by the progressive dysfunction and then loss of neurons. Three major categories of neurodegenerative pathologies can be identified: dementias (for example Alzheimer's disease, frontotemporal dementia, Lewy dementia); neuromuscular pathologies (for example amyotrophic lateral sclerosis, multiple sclerosis, dystrophies, miastenia); and movement disorders (for example Parkinson's disease, multisystemic atrophy, dystonias, ataxic syndromes). The traditional method of classification of neurodegenerative diseases was based upon the original concept of a clinical-pathological correspondence whereas the modern concept of neurodegeneration involves greater attention being paid to the genetic-molecular aspects, with consequent implications for the use of the current clinical practice of genetic and biochemical markers. In addition, one should take into consideration that the onset of many neurodegenerative pathologies, above all those involving dementia, can be traced back to an early stage in life and be seen as the evolution of mental disturbances present at that stage.

Epidemiology

In recent years various documents of the World Health Organisation have appeared in which emphasis is laid upon the increase in neurological and mental pathologies, as well as behavioural disorders, in the general population. Although these pathologies are responsible for only 1% of deaths they make up 11% of the global burden of disease, with an estimated increase by the year 2020 of almost 15%. It is estimated that 25% of families have a patient with neurological and mental disorders, or behavioural disorders, with grave economic, social and health-care consequences which are difficult to quantify, and that by the year 2030 depression and Alzheimer's disease will be amongst the ten principal pathologies of the planet. A study carried out in Europe has calculated that the cost of neurological diseases in 2004 was 139 billion euros, without taking into account many indirect costs which could increase public costs by 25%-50%. It has been calculated that the costs of dementia will constitute in the immediate future a priority, together with the pathologies that are at the present time a priority at a national and international level such as HIV, cancer, heart disease, stroke and diabetes. Based on simple demographic data, it is envisaged that the costs of dementia will have increased by 85% by the year 2030, with an increasing contribution to this state of affairs being made by developing countries.

In Italy, according to the recent 'Report on the Consumption of Medical Products', the expenditure on pharmaceuticals that have a direct effect on the central nervous system occupy the fourth position both in the expenditure rankings (3,310 million euros) and in those relating to consumption (161 days of therapy for every 1,000 inhabitants every day). To this should be added the costs of hospitalisation and costs linked to the loss of working hours, which in the case of some neurodegenerative diseases, which are often gravely incapacitating, are clearly higher than those for other pathologies.

In Italy there are 17 million people over the age of sixty, that is to say 27% of the overall population. The old age index, defined as the ratio in percentages of the part of the population that is elderly (65 years or over) to the part of the population made up of young people (less than 15) places Italy second after Germany, with a ratio of 144 elderly people to every 100 young people. The demographic projections demonstrate an arithmetical increase in this indicator, and thus in Italy by the year 2051 there will be 280 elderly people for every 100 young people. As regards Italy, one can estimate that there will be about 1,500,00-1,700,00 people with neurodegenerative diseases, and of these 1,000,000 will have dementia, 270,000 will have Parkinson's diseases or related pathologies, 68,00 will have multiple sclerosis and about 5,000 will have amyotrophic lateral sclerosis.

It has been estimated that in the world there are about 36.5 million people with dementia, with 7.7 million new cases every year and a new case of dementia diagnosed every four seconds. The number of people with dementia should triple over the next forty years. Most of these people will live in low- and medium-income countries. A great deal of the evidence that is available in terms of primary and secondary prevention identifies seven potentially modifiable risk factors associated with the appearance of dementia caused by Alzheimer's disease: diabetes, hypertension during adulthood, obesity in adulthood, smoking, depression, a low level of schooling, and physical inactivity. It is calculated that about a half of the cases of dementia caused by Alzheimer's disease are potentially attributable to these factors as an overall category. It has been calculated that reducing each one of these seven risk factors by 10% or 25% could prevent from 1.1. to 3.0 million cases of dementia caused by Alzheimer's disease.

The surveillance systems as regards the state of health and illness of the population that are available in Italy at the ISS, estimate that 10% of men and 7% of women are diabetic, whereas 8% of men and 4% of women are in a borderline condition (intolerance to glucose). 23% of men and 21% of women have a metabolic syndrome. In addition, in Italy arterial hypertension afflicts on average 33% of men and 28% of women and 19% of men and 14% of women are in a borderline condition. As regards depression, it is estimated that about 7% of adults between the age of 18 and 69 report symptoms of depression and see their psychological wellbeing as compromised. According to the latest data of the OECD, Italy is below the European average as regards levels of participation in the system of education and training for young people between the ages of 15 and 19 and for young people between the ages of 20 and 29. As regards lifestyles, the habit of cigarette smoking in Italy affects 33% of men (with an average of 17 cigarettes a day) and 23% of women (with an average of 13 cigarettes a day). 10.5% of Italians are obese and 30.1% can be defined as sedentary. In the future it will be necessary to act upon the scale of these factors in order to prevent dementia.

Health-Care Policies

The National Health Plan of 2011-2013 has its foundations in the principles of public responsibility for the protection of the right to health of the community and of individuals; of universality; of equality and fairness in access to services: of freedom of choice: of information and the participation of citizens; of free care within the limits established by the law; and of overall care coverage as defined by the LEA.

As regards the pathologies that constitute problems of great medical and social relevance, express reference is made to degenerative and incapacitating neurological diseases and dementia because: they generate situations of very grave and not remediable disability with a chronic development whose pathogenetic trigger mechanisms are not known, and this in the context of an absence of therapeutic instruments capable of weakening them or at least stopping their degenerative processes; they have a devastating psychological and operative impact on families which are called upon to take responsibility for burdens, of an economic character as well, which are inversely proportionate to the supply of care provided by the state service; they are responsible for high overall costs of care which can only be contained through an coordinated and efficient response on the part of the health-care system; and they raise complex and delicate ethical questions which institutions and the country are called upon to address.

Italy still does not have a document containing a general strategic programme such as a National Plan for Dementias, which, indeed, is present in nearly all other European countries. In reality, such a plan was drawn up by the Ministry of Health during the course of 2011 and was sent to the Unified Conference for technical discussion and debate with the regional governments, but it is still awaiting the observations of the inter-regional coordination body. This process, however, started again in the month of September after months of interruption with a series of meetings organised by the Ministry of Health with the regional points of reference.

For the first time the National Prevention Plan (NPR) of 2010-2012 included dementias and stressed the importance of overall clinical governance of the problem with the establishment of clinical care pathways based upon the evidence of the best available practices. This plan also envisaged 'central actions of support' for regional planning but unfortunately only two regional governments gave priority to this subject.

Within the general framework of health-care policies, reference should be made to the national plan entitled 'Obtain Health. Make Pro-Health Choices Easier' which was approved by the government in May 2007 in agreement with the regional governments and the governments of the autonomous Provinces. The 'Obtain Health' project set for itself the goal of investing in the prevention and control of chronic diseases in order to improve the quality of life and wellbeing of individuals and society as a whole, promoting healthy lifestyles and acting in particular on the principal risk factors related to chronic degenerative diseases of notable epidemiological relevance.

The primary goal is to act in an integrated and coordinated way as regards four principal modifiable risk factors (smoking, alcohol, bad alimentation and physical inactivity) which are responsible for 60% of years of life in good health lost in Europe and Italy. This risk factors must be addressed not only from a health-care point of view but also as authentic social phenomena. These risk factors as a whole have also been directly and indirectly associated with the appearance of dementias.

Research

Research in all its multiple expressions (basic research, translational research, epidemiological research, clinical research, genetic research, pharmacological research, and psych-socio-educational research) constitutes a real challenge in trying to understand the origins of neurodegenerative diseases and above all in being able to control them and improve levels of treatment and care for people with them and their family relatives. During the last twenty-five years numerous research projects have been financed by the Ministry of Health and by the Ministry for Universities and Scientific Research on dementias and neurodegenerative pathologies.

In this field reference should be made to the recent European project ALCOVE (Alzheimer Cooperative Evaluation in Europe) which was concerned with the policy to be adopted towards dementia. This European joint action involved thirty partners from nineteen countries, amongst which, representing Italy, the Higher Institute of Health Care, and its objective was the improvement in our knowledge about this pathology and its consequences and the stimulation of reflection on the quality of life of people with dementia, the concept of autonomy in relation to them, and their rights. The final recommendations of the ALCOVE Project centred around four specific areas: epidemiology, diagnosis, support systems for the management of psychological and behavioural symptoms (BPSD) of people with dementia, and ethical aspects (rights, autonomy, dignity).

As regards the epidemiological dimension, future studies were recommended on the incidence of dementia, respecting, however, standards of high quality such as those established by the Alzheimer's Disease International Report of 2009, adopting the clinical criteria in force (DSM IV and NINCDS-ADRDA for dementia caused by Alzheimer's disease) and – in order. to promote new knowledge in this field – the new criteria of the National Institute on Aging. Studies should also be promoted on the prevalence and incidence of dementia in people under the age 65 in order to establish in a more effective way the frequency of a phenomenon that is still not known about and which is very heterogeneous. Epidemiological studies should be carried out in the same geographical areas taking into account different decades in order to monitor the possible phenomenon of a decline in dementia, as is suggested by some evidence cited in the literature in the field. It also appears to be of urgent importance to gather data on the use of anti-psychotics in people with dementia in a systematic way and to look at future trends in different contexts (communities, home care, memory clinics, health-care homes) in all the member States of the European Union. The gathering of information on the use of anti-psychotics, in association with other quality indicators (for example the use of physical restraint in people with grave dementia resident in the USA), is indispensable in promoting – through national campaigns – an appropriate use of these medical products and in reducing the risks associated with their use. Improving the gathering of data on socio/health-care services for dementia is also of urgent importance. In particular, a minimum set of data agreed upon by the various member States should be adopted for the sources of administrative, clinical and epidemiological data, as well as other pertinent sources.

As regards diagnosis, the importance is stressed of the centrality of the person. In particular, a rapid diagnosis of dementia must be available to all citizens that request it the first time that an alteration in cognitive functions is observed. The fear and stigma associated with dementia must be reduced. This is the prerequisite for increasing the number of people who undertake a diagnostic pathway. The rights and the wishes of people with a possible diagnosis of dementia should be of primary importance in following the process of assessment that leads to a diagnosis. Communicating and receiving a diagnosis of dementia constitutes the central action in the complex process of adaptation to the disease. The needs of the individual and of his or her family or loved ones are of primary importance in the process of assessment and diagnosis and in post-diagnosis action. In planning national strategies for dementia possible questions relating to the staff involved and the services should be taken into account. Medical doctors involved in primary care, in the RSA and in hospitals should be trained and should receive instruments to support evidence-based decisions that are able to help them in the process of identifying dementia. Support instruments should be developed for the early identification of dementia by family doctors, and these should be assistance provided with other specialists, diagnostic guidelines, training and case management. Secondary specialist care services can improve the achievement of a swift diagnosis but there nonetheless remain many critical points in the adoption of this model given the absence of specialist expertise in contexts outside urban areas which have a low population density.

The recommendations relating to support systems for the management of psychological and behavioural symptoms (BPSD) of people with dementia highlight how these are a source of care-based burdens and depression for caregivers, as well as an increase in levels of institutionalisation for people with dementia. All the member State should develop a three-dimensional holistic strategy directed towards the development of care institutions and organisations that deal with BPSD; individualised initiatives for patients and caregivers (‘individualized patient and family carers’, IPCI) which combine psycho-social activity and pharmacological therapies; and, lastly, the expertise of socio/heath-care professionals (‘skilled work force’, WFS). These three dimensions connected with support systems for BPSD should be applied and implemented during every stage of the pathway of the patient: for the prevention and management of minor BPSD, for major crises of BPSD, and for the post-crisis stages, as well as secondary prevention. These applications should be planned on the basis of a close cooperation between decision-makers, socio/health-care services, professionals, associations of patients and family relatives. Information for the public on the prevention and management of BPSD, and on the risks of anti-psychotics, should form a part of sensitisation campaigns to reduce the fear and stigma connected with dementia. Mobile clinics should be developed for people with BPSD because preventing and managing BPSD early on is of crucial importance. These activities taken as a whole will increase the ability of people with dementia to live in their own homes for as long as possible. Mobile teams should be created which have specific tasks in providing assistance in relation to BPSD, in the context both of home care and of RSA. Respite care in necessary because it is crucial in supporting caregivers and giving them an opportunity, when this is required, to suspend temporarily the care that they provide to patient. An analysis of the literature in the field demonstrates that good health in a caregiver can prevent BPSD. Respite care includes day centres, temporary homes for people with dementia, and the presence of professionals at home to support caregivers. Units must be created for BPSD in the RSA and in hospitals because the development of this kind of unit involving assistance or admission has already been shown to be of notable help for people with major BPSD in various European States. The use of a socio/health-care dossier shared with the patient should be promoted, inasmuch as it constitutes an optimal instrument which is indispensable in achieving a multidisciplinary approach. A multidisciplinary team led by a nurse who understands psycho-motorial and occupational therapists has been shown to be useful in the prevention and treatment of minor BPSD in people with dementia who are cared for at home. As regards more grave BPSD, the action of a medical doctor and of a psychologist can be useful in the prevention of emergency admissions to hospital. In terms of public health care, the front line policies for the prevention and management of BPSD should be psycho-social interventions (PSI), and in particular the first level should be made up of psycho-educational programmes. This is because of the fact that PSI are effective in dealing with behavioural disturbances (agitation, aggressiveness, outbursts of anger, depression, and repetitive forms of behaviour that are different from psychoses) and are safer than anti-psychotics. First of all more precise assessment of PSI should be carried out in association with non-pharmacological therapies in order to identify which is the most effective strategy. This assessment must be carried out in economic terms as well. The psycho-educational programmes must be a part of national programmes for dementia. This is because of the fact that PSI and psycho-educational programmes are effective in preventing BPSD and are easy to implement. It has been demonstrated that there is an increase in their efficacy if a theoretical model is used and if there is the active participation of the caregivers.

The recommendations relating to the rights, the autonomy, and the dignity of people with dementia constitute an authentic emergency from an ethical point of view. A person who has been diagnosed as having dementia should not be automatically seen as being unable to exercise his or her right to choose. Competence must be assumed in the case of people with dementia during the course of their illness. When a person with dementia is unable to decide on his or her own, a proxy must be involved who has been identified and belongs to the system of care that is provided to that person. Only when a person with dementia is no longer capable of deciding must the proxy and the professional entrusted with providing him or her with care refer to prior provisions (if they exist) or to the previous values and interests of the patient. The competence of the person with dementia must be assessed using a case by case approach and should be repeated for every important decision regarding his or her care and treatment. When one assesses the competence of a person, contextual factors must be taken into consideration, and these include medical, psychological and social factors. An assessment of the competence of a person in taking decisions about care and treatment must be engaged in by a qualified and expert health-care professional. In many cases, but not in all cases, this person will be the medical doctor responsible for the individual concerned. However, this person should not decide on his or her own in all cases and situations. If this is thought suitable, he or she should take into account the opinions of other people (medical doctors, acquaintances and family relatives, health-care workers, social workers, psychologists etc.). Further research to achieve the development and approval of effective and practical instruments of assessment appears to be necessary, above all for people with a progressive cognitive disturbance, which is what dementia is. A biological testament should form a part of a wider context of the prior planning of care. A biological testament is a means by which to provide care of a higher quality in line with the desires and wishes of a person with dementia and not a goal in itself or the final product of a prior planning of care. National authorities are invited to provide a legal framework in which can be placed a biological testament that is suited to the specific needs of the person with dementia. Suitable models and good practices specifically for people with dementia should be further developed and disseminated given that all the stakeholders – patients, family relatives, professional and non-professional caregivers, health-care organisations etc. – must be made aware of the specificity and the complexity of the prior planning of care and a biological testament for people with dementia. Although the use of a biological testament should be encouraged, nobody can force the drawing up of a biological testament. Whenever a person does not wish to address questions connected with his or her future treatment or care, or questions connected with the end of his or her life, this wish should be respected. Medical doctors and other health-care workers involved in providing care to people with dementia must be suitably trained in the prior planning of care and in the use of a biological testament.

Conclusions

The subject of neurodegenerative diseases constitutes a real challenge for modern society. Their impact in economic, social and ethical terms is notable and this will become increasingly the case in the immediate future both in Western countries and in developing counties. The complexity of this phenomenon perhaps requires, for the first time in the history of medical science, an extraordinary capacity for governance that is able to integrate skills and forms of knowledge that are very different from one another. All of this should be effectively directed towards improving levels of care for the millions of people who are afflicted with these diseases and their family relatives. ■

4. The Concept of Sustainable Treatment as a Response to the Risk of “Rationed Treatment” in the Chronic Condition of People with a Neurodegenerative Disease

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There is growing concern about the increase in the incidence of neurodegenerative diseases in elderly people, together with an alleged demographic change fueled by a longer lifespan and diminishing birth rates. With the loss of the traditional family structure, society becomes increasingly involved in care for elderly persons. It is believed that the resources available to society are insufficient to cope with this growing demand. As one of the consequences there is an increasingly aggressive call for the rationing of resources and, as the most radical way to solve the problem, the call for a legalization of assisted suicide and euthanasia.

The Pope Emeritus Benedict XVI characterized the current problem as a test for the humanity of modern societies. Moreover, the Catholic Church as one of the biggest health care providers worldwide cannot stand aside and is therefore particularly challenged. That is why it is our responsibility to explore the question whether there is a concept of a sustained human solution for the problem.

In order to address this question, the current situation has to be carefully analyzed. It is obvious that traditional concepts need to be adjusted. The traditional approach teaches that science and economics, if only adequately applied, have the potential to find a solution for practically all problems. Indeed, the last century brought spectacular solutions for major medical problems thanks to scientific discoveries. A better understanding of disease mechanisms generated better diagnostic and therapeutic tools which finally proved to effectively control diseases. Examples of such a successful positivistic approach include the fight against most infectious diseases, advances in the prevention and cure of different types of cancer and, perhaps most importantly, the effective treatment of pain. Particularly the latter allowed impressive advances in medicine which effectively helped to limit human suffering.

Paradoxically, advances in science and medicine are partly responsible for the current problems. Advances in modern medicine are closely related to the higher number of chronic diseases and an increased lifespan. In the case of neurodegenerative diseases, research has so far failed to find an effective cure. Scientists are feverishly investigating the missing link between age and neurodegenerative diseases. However, although the results of these studies can be expected to shed more light on both healthy and unhealthy ageing, and may even help to develop life-long strategies to prevent the onset of neurodegenerative diseases, the confidence that science will completely solve the problem is lost. Despite the fact that financial support for research in this field has been dramatically upgraded, this has not restored the former confidence that existed. Individual attempts to financially secure old age have drastically boosted the volumes of pension funds. But even if these funds survived the recent financial crisis, they have failed to generate the desired security.

Still, there seem to be at least some successful attempts to cope with the problem in the traditional way. Emeritus Ltd, the self-proclaimed "leader of the assisted living industry", is a commercial specialist in the care of elderly people. This company was very successful on the stock exchange with its slogan "our family is committed to yours". However, this commercial approach to solving the problem of the increasing demand for care for elderly people has recently been characterized by a jury as "fraud". The company was sentenced to an incredible 22 million dollar fine which makes it another demonstrative example of the failure of traditional market-oriented concepts to generate a sustainable solution.

Taken together, all the beliefs and techniques we so successfully apply in our modern societies seem to fail in the face of the growing number of elderly patients with neurodegenerative diseases. We are witnessing the crumbling of the Tower of Babel and therein the smashing of the confidence that mankind can solve all problems, will finally reach the sky and ultimately be like God. This confidence is lost; chaos, fear and panic prevails. Also, solidarity ceases and communication becomes impossible because people start speaking in different tongues, i.e. different concepts.

Indeed, the crumbling of the Tower of Babel closely reflects the current situation. A reading of the Tower of Babel teaches us a lot about the bases and origins of the current problem: it is the *ratio*-centered materialistic pride of mankind which makes us believe that with sufficient material resources alone man can create his own universe and govern the world. This idea is deeply rooted in our modern societies and determines their anthropologic outlook.

This anthropologic outlook based on a utilitarian philosophy is the deeper reason for the growing panic and the public paranoia that we are currently witnessing. The utilitarian conception of the value and dignity of man is heavily focused on the rational ability of man and his capacity to increase the common good of society. As Thomas Hobbes declared: "Human dignity is the public worth of a man… the value set on him by the commonwealth". This idea of man inevitably decreases the value of the lives of elderly people and renders life entirely worthless in the case of a neurodegenerative disease. Herein lies the explanation for the panic in modern societies. The logical consequence of an anthropology based on a positivistic, utilitarian philosophy is that each person's life inevitably becomes worthless with increasing age. Our human dignity will be lost as soon as age or disease renders us unable to add anything to the common good. Our lives will even more be endangered from that moment, when we are no longer able to express our needs and defend our interests. Accordingly, the paranoia that has stricken people in Western societies is absolutely realistic. The danger arises from the materialistic and utilitarian philosophy of our societies which inevitably leads to a "war against the weak".

The utilitarian philosopher Savulescu from the Oxford Center of Ethics provides a good example of the consequences of strict utilitarian thinking. He sees only one possibility for elderly people to regain at least some final dignity for their lives: His proposal is to commit suicide and become an organ donor. Thereby at least elderly people can help to ease the problem of organ shortages for transplantation and support the fitter and stronger in society (D. Wilkinson and J. Savulescu, *Bioethics* 2012 January; 26(1): 32–48).

With this analysis of the current problem we can return to the original subject of this paper: the question of whether there is a sustained and human solution for the care of elderly patients with neurodegenerative diseases. It is obvious that a sustainable solution has to come from a complete change in the current anthropological view. This is offered by Christian teaching which sees man as being in the image of God. Man has a value in himself: he does not serve a purpose. Therefore, it is irrelevant whether a human being is able to add something to society or not. Disability in this context clearly does not affect the dignity of a person. Rather, the disabled person has an inherent dignity which brings him or her closer to Christ. Even more, the caregiver can get closer to Christ; he or she can get closer to eternity when he or she cares for the sick.

In fact, care for the elderly patient lifts us closer to heaven. Archbishop Zimowski, the President of the Pontifical Council for Health Care Workers, on the occasion of the World Day of the Sick in Altötting in Germany this year, put it this way: "The hospital is the place where heaven and earth meet". The sick person brings heaven closer to us and we, as caregivers, are lifted closer to heaven.

Indeed, the patient with a neurodegenerative disease not only brings us closer to Christ: he or she also teaches us a lot. These patients live a life that is not entirely *ratio*-centered. As in the case of a child, it is focused on the present detached from daily concerns, with no worries regarding the future. The inability to communicate verbally which stigmatizes these patients in the eyes of utilitarians does indeed offer a rare chance: As Pope Benedict XVI put it: "If God speaks to us… in silence, we in turn discover in silence the possibility of speaking with God and about God. Silence is an integral element of communication; in its absence, words rich in content cannot exist" ('Message for the World Day of Social Communications', 24 January 2012.) And did we not all witness how our Holy Father John Paul II was able to teach us the Gospel at the end of his life without a single word?

So, Christian anthropology offers an excellent basis for a sustainable solution for care for an elderly patient with a neurodegenerative disease. But I hear the objection that this is only a theoretical approach which cannot be achieved in practice. Like me, many of you in the auditorium are directly or indirectly involved in the management of health care. You have to be courageous to postulate a human solution based on Christian teaching for the solution of demographic changes and health-care problems in modern societies. You have to defend yourself against the accusation that this approach is pure social romantics, not feasible in practice and entirely unattractive for most people in society.

The question is: Is the Christian approach a sustainable and feasible solution to the problem? The answer is easy! Of course, it is! And we can prove it! The Christian solution to care of the weak was implemented two thousand years ago and has since then always been very successful!

As His Excellency Archbishop Zygmunt Zimowski put it: "The Church, adhering to the mandate of Jesus, '*Euntes docete et curate infirmos*' (Mt 10:6-8, Go, preach and heal the sick), during the course of her history, which by now has lasted two millennia, has always attended to the sick and the suffering".

Indeed, curiously enough, the solution for the current problems was already generated two thousand years ago and has been proven to be effective and attractive since then. In fact, the situation two thousand years ago was considerably more difficult than it is today. Christianity arose in a historical context with problems at least as difficult as the present ones. Two thousand years ago the Christian belief that every human being is in the image of God and deserves full human dignity was completely unheard of. Moreover, the belief that suffering brings you closer to heaven was revolutionary and completely against mainstream thinking. However, this message exerted such a powerful attraction on the desperate people of that time that an incredible fast expansion of Christianity could be observed all over the Roman Empire in a very short period of time.

The New Testament redefined anthropology and human dignity. The Son of God had no earthly power; instead he suffered. The most powerful in the universe was crucified in the most shameful way. This, of course, is in clear contrast with the idea that the dignity of a person is based on the ability to defend his or her needs. On the contrary, the Christian belief is that the loss of all earthly power and love and care for the sick and weak brings us closer to Jesus and eternal life.

On the basis of this Christian faith, 900 years ago a group of crusaders associated with the Amalfitan Hospital in Jerusalem laid down their armor and became a nursing Order, the Order of St. John of Jerusalem, today known as the Order of Malta. The anthropological view of these men was completely against the mainstream. They treated their patients with the highest possible respect. The patient was nothing less than "Our Master the Sick". This was the anthropological basis of their care. And on this basis it was only natural that the knights personally served meals to their patients on silver trays.

So Christian belief offers a solution to the problem, but is it a sustainable solution, has it indeed survived the centuries? Is it still attractive today? The answer, again, is: yes! For instance, the Order of Malta is again one of the greatest health-care providers in Germany. It is particularly active in the field of care for elderly patients with neurodegenerative diseases. On the basis of the Sylviahemmet Project, a project designed in Sweden by Queen Sylvia who had to care for her mother who had Alzheimer's disease, a network of care for elderly patients with this disease is currently been developed in Germany. This especially includes the social environment of the patient outside the hospital. In this network, everybody is being trained to treat the patient professionally and with respect and compassion. Even the taxi driver who may drive the patient back home from the hospital is included.

But there is still concern about demographic changes and the question of whether the younger generation can be attracted by the Christian concept of care for elderly patients with neurodegenerative diseases. Has the quest of our Holy Father Pope Francis who advised the Church to go to the outskirts been heard by the younger generation? I believe, the answer is again a clear yes! Going to the outskirts is very attractive for young people. For instance, young adults from the Order of Malta from all over Europe care for severely handicapped young people in Lebanon every year. For their work in Lebanon and their "Lebanon on Stage" fund raising theatre, the project received the prestigious Westfalian Peace Award together with the former Secretary General of the United Nations, Kofi Annan. Similar projects for handicapped and elderly people are organized by the young generation all over the world. Yes, Christian solidarity has survived nine centuries and has not lost its attraction for the younger generation. It is the basis of a sustained solution of our current problem. Therefore, our duty is to spread this joyful message in a desperate society which threatens to sink into a culture of death.

Having said and understood all of this, let us be realistic! Care for an elderly patient with a neurodegenerative disease is anything but easy. Each one of us who cares for these patients in work or in the family has experienced caregiving as a major challenge. And sometimes we feel we are in the wrong place at the wrong time. Why us? Can't we live our lives with more freedom according to our personal needs and plans with less obligations?

Let us take comfort in the picture of Simon of Cyrene. This man, also, must have felt that he was in the wrong place at the wrong time. He came back from his daily work in the fields looking forward to some rest. Suddenly, he was forced to change his plans and had to help a man suffering under a cross. He had to completely change his original plans: instead of walking into Jerusalem he had to turn around and walk to Golgotha. This must have felt an incredible misfortune and injustice. He must have asked himself why this misfortune had hit him, a foreigner from Cyrene, who was not related to this poor man. Where are the supporters of this man, his family, his friends to help him in this desperate situation. Why him? He is not responsible for this crucifixion. The ones responsible for this should provide adequate professional help! And even more, this man is obviously bound to die. Why extend his meaningless suffering, this unworthy life? Let him die straight away, have mercy on him at the end his life and end the suffering straight away. This life does not make sense any more; helping this man only extends meaningless suffering. Here the Bible tells another story of incredible contemporary relevance which clearly describes a situation that affects most of us during care for elderly patients.

But now, let us see how things develop for Simon. He puts himself under the cross, into a helping position, following the path of Christ. This will prove to be an incredible turning point in his life: he has accidentally become part of God's plan. By chance he has been put into a position to help the Messiah; to heighten his life to a level where he is able to intimately support divine action. This he will only realize much later, but he will be grateful that his life received a higher meaning exactly at the moment when he felt that he was in the wrong place at the wrong time.

Simon of Cyrene's story teaches us that the moments of greatest despair may actually be the most privileged moments in our lives. They are sent to us so that we can reach a more intimate relationship with God. Similarly, the dramatic situation in which our societies seem to find themselves with increasing numbers of elderly patients with neurodegenerative diseases may be sent to us to radically change our original plans and attitudes and take up the cross and follow Christ. As difficult as this may be at the beginning, it may prove to be a privileged moment in the history of our societies. So instead of desperation this joyful message has to be sent out to our panic-stricken modern societies to liberate them from the paranoia that old age and the loss of rational abilities will render them unworthy and without support. There is a sustainable solution to this problem which has proven to be effective over the last two thousand years. Society does not have to sink into a desperate culture of death, in a war against the weak where elderly patients with neurodegenerative diseases are eliminated. Instead, there is a solution which provides help to the elderly and sick person and lifts the care giver closer to heaven. ■

SECOND SESSION

RESEARCH AND TREATMENT: CURRENT AND FUTURE UTILITY

1. Genetics and Preventive Medicine

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The pressing request for effective medical products and ones that are not toxic is a priority in pharmaceutical research. Medical products are industrial products which have to meet the requirements established by society to assure its health and its social and economic development. For this reason, they have to be effective with every individual and above all they must not cause adverse events or induce risks of a pathology that is different to the one the patient is being treated for. The principal objective of pharmaceutical research is innovation in therapy after the discovery and the development of new compounds which are able to assure an incremental benefit for the patient and/or for health care. In qualitative terms, pharmaceutical innovation has been the subject of assessment by a number of authors who, when analysing the dossiers deposited with the regulatory authorities for the registration of medical products, have observed that only a small percentage of these have added value compared to previous forms of treatment. The availability today of genomic knowledge allows the process involving the discovery of new medical products to be more effective through the identification of new biological targets ('the most appropriate target for each illness') and to improve the effectiveness and the tolerability of the medical product through the personalisation of preventive or therapeutic treatment on the basis of the genetic characteristics of the patient ('the medical product that is most appropriate for each patient').

By the phrase 'personalised medicine or precision medicine' is meant today the model of medicine that is characterised by the possibility of identifying the susceptibility of an individual to common illnesses, measuring his or her level of risk, personalising the therapy on the basis of the genetic constitution of the patient involved and offering new therapeutic options based on the interaction of medical products with new molecular targets in order to assure the best outcome possible in health terms.

The attainment of such objectives does not depend only on the development of scientific knowledge. It also depends on an appropriate management of the ethical, legal and social implications associated with research and the application of new technologies. Personalised medicine is based upon a fundamental assumption: differences between people, between their genetic inheritances and between the responses that each group of cells gives to a possible genetic variation. On average, human beings differ from each other by about six million nucleotides (the units that make a up a DNA molecule) in their genomes. Each person, therefore, must be treated as a unique individual and not as a sort of medical statistic. It is precisely by studying the genetic profile of, or carrying out a specific genetic test on, each individual that one can assess the efficacy of a specific medical product, its possible adverse effects and even the most recommended dosage for each individual. At the present time there are over three hundred medical products for which is envisaged or recommended the carrying out of a test. And in some cases they are even extraordinary, as for example happened with 'Abacavir', the active principle of a medical product for the treatment of AIDS. Before the pre-treatment test was introduced in 2008, very grave cases had been registered of adverse reactions that had even led to death. Now, with the genetic test, the danger has been removed. In the field of oncology, tests are often used at two levels: to establish *ad hoc* therapies and to assess the individual's risk of falling ill. However, to carry out the test the pathway is a long and detailed one and envisages the family doctor being the first filter, identifying the patients that really need genetic consultancy. One thus comes to the expert geneticist who assesses the risk of that particular individual through questionnaires, conversations and inquiries into his or her state of health, history and lifestyle. Today strategies are being developed for personalised medicine by now in all fields, without exception, from so-called complex (cardiovascular, neurodegenerative, immunological, cancer) diseases to diets. Personalised medicine is revolutionising practical medicine and within ten years everyone will have a sequenced genome as part of their clinical dossier and thus the appropriate medical product.

The development of personalised medicine depends on the availability of genetic tests that predict illness and responses to therapy. The demonstration of the clinical value and utility of these tests constitutes a fundamental pre-condition for their adoption in medical and health-care practice.

Predictive tests of genetic 'susceptibility' to illness (or also pharmacogentic tests) constitute the basic technology of so-termed predictive medicine, that is to say the capacity to identify the susceptibility or the resistance of a person to a common illness (or the susceptibility to developing a side effect or a non-response to a given medical product).

The Ethical, Legal and Social implications of Personalised Medicine

The ethical, legal and social implications of personalised medicine, with reference both to research and to its application in medical practice, are not quantitatively different from those of genetic research in general and thus the conceptual and normative instruments drawn up for genetic research can be applied, albeit with certain specificities, to personalised medicine as well: the management of genetic information and aspects connected with informed consent, to privacy and secrecy; stratification or differentiation between patients: and fairness in access to medical care and treatment.

The fundamental problem of genetic research as regards the development of personalised medicine, whether directed towards the development of predictive tests for illness or towards predictive tests for responses to a medical product, relate to the control of the flow of information. In order to identify the relationship between genotype variability, a predisposition to an illness and responses to medical products, research needs to collect, conserve and analyse DNA samples that are able to generate an enormous quantity of information which are correlated to other characteristics of the individual involved. This is a need shared by the whole sector of genetic research and it has recently been the subject of broad debate in relation to the creation of certain local or national projects of gene banks to be used for the identification of genes that involve susceptibility to illnesses. The nature of the information generated by a genetic test is variable according to the character that the test explores and the capacity of the test to predict the phenotype that is studied (for example an illness). Equally variable are, therefore, the ethical and social implications that can derive from the test. One is dealing here in essential terms with creating the conditions to pursue this benefit, avoid negative side effects in terms of justice, and achieve fairness in access to medical care and treatment. This phenomenon could intensify in the future for reasons connected with the policies of investment in pharmacological research by pharmaceutical companies. Indeed, stratification is already held to be a relevant factor for the development of new medical products that aim at specific genetic features of grave diseases, such as cancer, as these tests gradually become less expensive and increasingly reliable in terms of predicting the efficacy and the safety of medical products, and this is true for the entire field of pharmacological research. In itself this trend many be seen as undoubtedly beneficial, but its pursuit could be obstructed by socio-economic factors and could, however, give rise to unfair consequences. There can be no doubt that research in pharmacogenetics is destined to stratify into subgroups both patients (on the basis of their profiles of response to medical products) and illnesses, giving rise to a new 'molecular taxonomy of illnesses', that is to say the idea that certain illnesses, hitherto understood as a single condition, constitute in reality, from a genetic point of view, a more heterogeneous framework and thus require differentiated forms of treatment, that is to say forms of treatment that are 'made to measure' for each individual patient and with the least possible burden of side effects.

The ethical basis for the enrolment in clinical studies of responsive individuals alone, and for the exclusion of non-responsive individuals, is already present in the rules that at the present time regulate the carrying out of clinical trials: the non-exposure of the individuals involved in the study to useless or excessive risks or anyway ones that are compensated for by a benefit – if we do not know that the specific individual involved does not respond to a given medical product, to involve him or her means to expose him or her to a useless risk, without any compensatory benefit for the patient or for research.

One of the critical points raised by genetic research into a population has been 'group consent', a subject that is at the centre of the discussion about the ethical and social implications of genetic research on a population in all projects – correlated with susceptibility to illnesses and to responses to therapies that have been carried out hitherto. The central idea arises from the concern that a given individual, even though he or she may not have taken part directly (or has refused to do so) in a research project, can receive from it nonetheless a psycho-social injury (in the form of stigmatisation or discrimination) as a result of being perceived as the member of the social group, which is very identifiable, on which the research has been carried out. An example of this has been posited to be pharmacogenetic research which demonstrates that a social group identifiable on ethnic bases is a non-responder to a given medical product in certain conditions which is then translated into forms of discrimination in access of treatment which in the specific case could be connected with prejudices of an ethnic background and could involve all the individuals belonging to the group, even those who did not take part directly in the research. It is, however, known that the genetic variability within a group can be even greater than between groups and thus the problem is not so much scientific as one of public perception. The solution to these critical points thus envisages a profound work of formation and information in relation to the population involved and it is hoped – in special cases or when the research concerns groups that are seen as vulnerable – that the obtaining of informed individual consent is preceded and accompanied by a correct campaign of sensitisation and consultation

Conclusion

The results produced by genomic research over the last decade have, in substance, allowed the development of personalised medicine (genetic predictive medicine) and the introduction into clinical practice of the first applications based on new technologies that are able to identify susceptibility to common illnesses and to predict responses to pharmacological treatment.

An appropriate introduction of the new technologies specific to personalised medicine requires the assessment of tests of efficacy which are needed to direct decisions relating to their use. These tests must be generated through studies that are able to verify the causal relationship between associations of genotype and phenotype (whether illness or response to therapy) which today with increasing frequency are identified thanks to the availability of extended sequencing technologies of the genome which are increasingly effective (NGS).

Further development of genomic and pharmacogenetic research requires an appropriate management of the ethical, social and legal implications and above all the adequate training of medical doctors, ethical committees, healthcare workers and administrators, citizens and patients. The recommendations drawn up by experts of different disciplines allow a management of most of the critical points raised by clinical genetic research and an assessment and balancing of benefits and risks in order to maximise the former and minimise the latter. ■

2. Biotechnologies: from Genomics to Proteomics

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Let us first of all define the terms of the title of this paper. By *biotechnologies* is meant in general technological development as applied to the study of living organisms or biological systems. According to this definition, human beings have used biotechnologies for thousands of years for the production of foodstuffs, textiles and other necessary objects by using microorganisms in culture such as yeast, bread, yoghurt, cheese, wine, beer and vinegar. However, in recent years the term 'biotechnology' has come to refer to the use of *genetic engineering* and its associated technologies. This definition in recent years has had a broad variety of applications, ranging from medicine to agriculture.

Genomics and proteomics. These terms define the new approaches to biotech/biomedical research which have been made possible today by technological advances in the field of computer sciences and the use of data.

Genomics and proteomics by now form a part of a new technological and scientific sector which is undergoing a rapid development and which is described by the term 'omics'. Omics constitute a vast discipline of science and engineering which analyses the interactions of biological information in various 'omics' and in particular genomics, proteomics and metabolomics. The suffix 'omics' is an example of a neosuffix that is employed in numerous medical terms derived from ancient Greek and which finish with the Greek suffix -ωμα. This suffix is used today in biology to refer to the totality of a set.

The principal objective of this discipline is: 1) the *mapping* of informative objects such as genes, proteins and ligands; 2) finding *relationships that involve interactions between objects*; 3) *the engineering of networks and objects* so as to understand and manipulate regulation mechanisms; and 4) *the integration* of the various sub-fields of 'omics'.

The word 'omics' derives from a neologism of the English language that refers informally to fields of study in biology that end in 'omics', such as genomics, proteomics and metabolomics. The suffix 'ome' is used for the subjects of study in these fields, such as genome, proteome and metabolome respectively. Omics aims at a collective characterisation and quantification of pools of biological molecules which are translated into the structure, function and dynamics of an organism or organisms.

Functional genomics seeks to identify the functions of the greatest possible number of genes of a given organism. It combines various omic techniques such as transcriptomics and proteomics.

By way of an example, other more sectorial omics are: *lipidomics*, which corresponds to the entire category of cellular lipids, including the modifications worked by a particular set of lipids, that is produced by an organism or system, and which studies on a large scale the pathways and networks of lipids. Mass spectrometry techniques are employed in this approach .Then there is *glycomics* which studies the sum of all the complex *sugars* produced by a living organism as well as glycan-joined molecules such as glycoproteins and glycolipids. 'Glycan' is another word used to refer to polysaccharides (chains of sugars). These polymers perform many roles in cells, amongst which participation in intercellular communication. Glycans, like complex lipids and glycolipids, are an integral part of the process by which tissues are kept together and the spaces between cells are occupied. Thus it is that glycomics is also an important part of tissue engineering. In addition, there is *metabolomics*. This is the study of the chemical processes that involve the metabolites. This involves a systematic study of the unique chemical impresses that specific cellular processes leave behind them, the study of the profiles of small molecules called metabolites.

1. Genomics

Genomics is a relatively new science that deals with listing all the sequences of the genome of a particular organism. The genome can be defined as the complete set of genes within a cell. Genomics, therefore, is the study of the genetic inheritance of organisms. The definition of the genomic sequence, however, is only the beginning of genomics. The genomic sequence is subsequently used to study the functions of the numerous genes (*functional genomics*) in order to compare the genes of one organism with the genes of another (*comparative genomics*) or to generate the three-dimensional structure of one or more proteins of every family of proteins, thereby offering clues as to their function (*structural genomics*). Genomics can be seen as the point of entry to draw near to other 'omic' sciences. The information in the genes of an organism, its genotype, is in large measure responsible for the final physical structure of the organism. which is called the 'phenotype'. However, the environment also has a certain influence on the phenotype. The genomic DNA, however, is only one aspect of the complex mechanism that explains the function of an organism – therefore decodifying the DNA is a first step towards an understanding of the process. However, in itself it does not specify everything that happens within the organism. The basic flow of genetic information in a cell is the following. The DNA is transcribed or copied in a form known as 'RNA'. The complete set of RNA (known also as its transcriptome) is subject to some modifications (cutting and pasting) in order to become the RNA messenger which takes information to the ribosome, the protein fabric of the cell, which then translates the message into proteins The human genome is of fundamental importance for health and wellbeing and is used by companies as a basis for innovations as regards many applications, ranging from the environmental to the medical.

Genomics is the name, therefore, that is given to the field of study and to the methodologies that are used to explore *the entire genome of an individual using high throughput systems for the sequencing of genomic DNA. In this area, reference is made to next generation sequencing and to exome analysis (WES) or entire genome analysis (WGS). In addition,* in genomics those factors are studied that *control* transcription on a large scale here as well through the use of *high throughput* systems for the detection of the mRNA, which is called 'array'. In this case we refer to the *transcriptome* which is the set of all the RNA molecules, including mRNA, rRNA, tRNA and other non-codifying RNA, that are produced in a cell or in a population of cells.

Advances in computer science and high-velocity technology have allowed the study of the relationships between the expression of various genes in a relatively short time.

We thus refer to *genomics*, which is the study of the genomes of organisms; to *cognitive genomics*, which studies changes in the cognitive processes that are associated with genetic profiles; to *comparative genomics*, which is the study of the structural and functional relationships of the genome through different species or biological lines; to *functional genomics*, which describes the functional gene-protein interaction and uses microarray techniques; to *metagenomics*, which studies metagenomes, that is to say genetic material recovered directly by environmental samples; and to *personalised genomics* which is a branch of genomics that is interested in the sequencing and the analysis of the genome of an individual. Once the genotypes are known, the genotype of an individual can be compared with the published literature in the field to ascertain the probability of an expected phenotype and the risk of diseases. It helps in personalised medicine. Lastly, there is *epigenomics* which is the study of the complete set of epigenetic modifications to the genetic material of a cell which is known as the epigenome. In this area technologies in the sphere of chips and *ChIP–Seq* are used.

2. Proteomics

Proteins are responsible for an infinite number of tasks within a cell. The complete set of proteins in a cell can be described as its *proteome* and the study of the structures and the functions of the proteins and what each protein is doing in a cell is known as *proteomics*. Proteomics is highly dynamic and changes from time to time in response to different environmental stimuli. The objective of proteomics is to understand how the structures and the functions of the proteins allow them to do what they do, that is to say how they interact and how they contribute to the vital processes.

One application of proteomics is known as 'expression profiles' where the proteins are identified at a certain time in an organism as the direct result of the expression of a stimulus. *Proteomics* also means the development of a map of the protein network where the interaction between proteins can be caused by a particular living system.

Proteomics allows us to map the modification of proteins in order to ascertain in a comparative way the difference between a wild type and an organism that has been genetically modified by a genetic mutation. Proteomics allows us to study protein-protein interactions in physiological conditions and conditions of illness. By *proteomics*, therefore, is meant the entire set of proteins, including the modifications brought about by a particular set of proteins, that is produced by an organism or a system. The techniques that are most in use are those relating to mass spectrometry. Examples of branches of study derived from proteomics are: *immunoproteomics*, which is the study of the large sets of proteins (proteomics) involved in the immunity response; *nutriproteomics*, which involves the identification of the molecular targets of nutritive and non-nutritive components of a diet and uses proteomic data from mass spectrometry for the study of protein expression; *proteogenomics*, which is an emerging sector of biological research at the intersection between proteomics and genomics – this term is commonly used to refer to studies that utilise data from proteomics, which are often derived from mass spectrometry, to improve genetic observations and post-translational modifications; *structural genomics*, which is the study of the three-dimensional structure of each protein codified by a given genome using a combination of experimental and modelling approaches. A recent development in proteomics applied systematically to the study of numerous neurodegenerative diseases is *redox proteomics*. The assumption of this is that proteins are important targets of reactive kinds of oxygen and nitrogen (ROS/RNS) and that there are numerous post-translational, reversible or irreversible modifications that can lead to a change in the structure and/or function of an oxidised protein. *Redox proteomics* is an increasingly emergent branch of proteomics and it is designed to identify and quantify the redox-based changes within a proteome both in a redox indication and in conditions of oxidative stress. It has by now been widely accepted that there is a correlation between the oxidisation of proteins and human illness, even though the clarification of causes and effects remains a challenge. An increasing number of biomedical data have provided convincing evidence regarding the involvement of perturbations in the redox homeostasis in a large number of physiopathological conditions and in ageing. Research directed towards a better understanding of the molecular mechanisms of a disease together with the identification of the specific targets of oxidative damage is urgently needed. In recent years proteomics, in combining mass spectrometry (MS) and methodologies based upon chemical affinity, has contributed in a significant way to the achievement of a better understanding of the oxidative modifications of proteins that take place in various biological samples in different physiological and pathological conditions. We are by now witnessing a growing number of original articles and articles expounding revised views that indicate how redox proteomics has a fundamental role in the study of oxidatively modified cerebral proteins in patients or animal models with Alzheimer's disease, Parkinson's disease and adrenoleukodystrophy because of the development of bio-markers as well as of pathogenic mechanisms in many human neurodegenerative diseases. ■

3. ROUND TABLE DEMENTIAS

3.1 The Diagnosis of Alzheimer's Disease

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Alzheimer's disease (AD) is a progressive neurodegenerative disorder with cognitive, behavioral and functional abnormalities. AD is the most prevalent form of dementia (link to epidemiology): it accounts for 70% of cases of progressive cognitive impairment in aged individuals,[1] age being the single most important risk factor. The prevalence of AD doubles every 5 years after the age of 60 and reaches 40% after 90.[2] The disease is linked with ageing, but it is not due to ageing, as exemplified by early onset cases, usually defined as symptoms starting before 65.[3] The dementia syndrome associated with advanced AD has characteristic clinical features that usually include various combinations of memory impairment, language abnormalities, impaired gestural skills (apraxia), disturbances of visuospatial functions and executive deficits. These cognitive and behavioral abnormalities interfere with the functioning of activities of daily living (ADL), with ADL impairment being a marker and core criterion for the diagnosis of a dementia syndrome.[4] A number of bedside tests, e.g. the Mini Mental Status Examination, can be used to provide a global quantification of the deficits and is useful for characterizing the stage of cognitive decline.[5] However, more detailed neuropsychological testing with standardized assessment of attention, memory, language, executive functions and visual-spatial abilities is required for quantifying the deficits of AD and may aid distinguishing AD from other degenerative dementias. In addition, various neuropsychiatric disturbances can be observed in patients with AD: apathy, dysphoria and agitation are common during the course of the disease.[6] The clinical diagnosis of AD has traditionally required the exclusion of alternative explanations for cognitive decline using blood testing and brain neuroimaging including computerized tomography (CT) or magnetic resonance imaging (MRI).

A. The Current Diagnostic Work-up of AD

Despite the fact that there is significant evidence for the benefits of early diagnostic evaluation, treatment and social support, the rate of diagnosis and treatment in people with dementia varies considerably over the world. However, general practitioners play a major role in the identification, diagnosis and management of patients with dementia. In many places multidisciplinary teams have been established to facilitate the management of the complex needs of patients and caregivers during the course of the dementia disease. Neurologists and other specialist physicians play a major role in these teams and clinics, together with other professionals with special training in dementia.

Clinical diagnosis

With the remarkable exception of autosomal dominant causes of dementia, there is no specific biological marker for degenerative dementias validated for clinical practice. Therefore, the diagnosis of AD is still made in terms of probability. The clinical diagnosis should rely on criteria that have been proposed to increase the reliability and accuracy of the diagnosis. The Diagnostic and Statistical Manual, third edition, revised (DSM-IIIR)[7] and the National Institute of Neurologic, Communicative Disorders and Stroke – Alzheimer' Disease and Related Disorders Association (NINCDS-ADRDA)[8] criteria have achieved a good sensitivity (average 81% across studies) but a low specificity (average across studies 70%) for 'probable' AD.[4]

1. Medical history

The clinical history is a cornerstone of medical practice and serves to focus the examination and investigations. The history should include the mode of onset (progressive memory disorders with spatial-temporal disorientation in most of cases), the pattern of progression and the impact on activities of daily living (ADL). Past medical history, current comorbidities and family history are important. Due both to the presence of cognitive deficit and to the possibility of anosognosia, it is important to obtain a history from an independent informant.

2. Assessment of cognitive functions

Cognitive assessment is central to the diagnosis and management of AD and should be performed in all patients. Quantitative neuropsychological testing of the main cognitive domains including memory, executive functions and instrumental functions, ideally performed by someone trained in neuropsychology, should be considered in patients with questionable, prodromal, mild, or moderate dementia whereas it is less essential in severely demented patients. The battery should investigate the following domains:

Global cognitive functions – The Mini-Mental State Examination (MMSE) of Folstein *et al.*[9] may help in the detection of cognitive impairment and its sensitivity increases, if a decline of the score overtime is taken into account.

Memory function – Memory has to be systematically assessed. Episodic long-term memory impairment is a characteristic feature of AD. Word recall, such as the Rey Auditory Verbal Learning Test (RAVLT), can distinguish between patients with AD and those without dementia.[10] However, an effective encoding of information should be controlled to exclude the influence of depression, anxiety and other emotional states on cognitive problems. Semantic cueing may also help in separating retrieval for storage deficits as proposed in the Free and Cued Selective Reminding Test (REF).

Executive functions – This impairment results in decreased verbal fluency with speech reduction, verbal stereotypies and echolalia; perseverations of mental set; retrieval deficits; attentional disorders; concrete thinking and in some cases disinhibition, impaired adaptation, and uncontrolled behaviors. These deficits are currently assessed by the Wisconsin card sorting test,[11] the Trail Making test,[12] the Stroop test,[13] the verbal fluency tests,[14] and the digit ordering test[15] which trigger the cognitive processes needed for executive functions.

Instrumental functions – Language (comprehension and expression with naming disorders), reading and writing, praxis (execution and recognition of reflexive or symbolic gestures), visual-spatial and visual-constructive abilities can also be involved during the course of AD.

3. Assessment of behavioral and psychological symptoms

Various terms, including 'behavioral and psychological symptoms of dementia' (BPSD) or 'neuropsychiatric features' are used to describe a range of symptoms that are common in AD and which contribute substantially to patient distress and caregiver burden. They are frequently a major factor leading to the prescription of psychotropic medications and to nursing home placement. Their temporal course varies, e.g. apathy, depression and anxiety tend to occur early in the course of AD with delusions, hallucinations and agitation appearing in the middle to late stages. BPSD may be worsened or caused by somatic co-morbidity. Patients with psychosis experience a more rapid cognitive decline than those without, and neuropsychiatric features may predict an increased rate of conversion to dementia in patients diagnosed with MCI.[16] The accurate identification of BPSD is essential both for the diagnosis and the management of patients with dementia, but often such symptoms may not be disclosed by patients or caregivers until they are intolerable or they precipitate a crisis.[17] Several rating instruments have been designed for this purpose, enquiring not only about the presence or absence of different symptoms but also about their frequency, severity and impact upon the caregiver. They usually rely upon the report of an informant who should have regular contact with the patient. Repeated use of such scales can also be useful in monitoring the effects of treatment interventions. Suitable scales include the Neuropsychiatric Inventory (NPI)[18] and BEHAVE-AD.[19] The most common neuropsychiatric feature of AD is apathy (72%), followed by aggression/agitation (60%), anxiety (48%) and depression (48%).[20] Apathy and inertia may occur independently of depressed mood and may be particularly frustrating for caregivers, especially in the early stages. Agitation and aggression may be very persistent and frequent causes of requests for institutionalization. Anxiety may manifest physically with tension, insomnia, palpitations and shortness of breath and also with excessive worrying and fearfulness particularly if separated from the spouse or caregiver. Depressed mood should be assessed independently of weight loss, appetite changes, sleep disturbances and retardation which may occur as features of AD. Delusions are common in dementia, usually of theft, intruders or imposters, often rather vaguely expressed and transient. They are typically based in forgetfulness and misinterpretation. Hallucinations, misidentifications and illusions can be observed in advanced stages of AD, particularly in those with impaired vision and hearing. Purposeless activities such as pacing and rummaging are characteristic of AD. Sleep disturbances may be secondary to other psychiatric features and may be associated with daytime drowsiness.

4. Assessment of activities of daily living

Decline in every day functional abilities is a major component of the dementia syndrome. Assessment of function in daily life is part of the diagnostic process and allows clinicians to evaluate the need for personal and/or institutional care. Different scales are used to objectively measure these abilities. These are based mainly on the interview with the patient and his/her caregiver. Two classical fields measured are basic or general (such as eating, dressing, etc.) and instrumental activities (such as the use of devices, shopping). Frequently used scales include the Alzheimer Disease Cooperative Study (ADCS) ADL Scale;[21] the Functional Activities Questionnaire (FAQ);[22] the Progressive Deterioration Scale (PDS);[23] and the Disability Assessment for Dementia (DAD).[24]

Neuroimaging

Traditionally, imaging was considered important solely as a means of excluding treatable causes of dementia. Neuroimaging is now the most important ancillary investigation in the work-up of dementia to aid in differential diagnosis and management decisions.

1. Computed tomography

Computed tomography (CT) is mostly used to exclude other illnesses that are potentially amenable to treatment, e.g. tumors, hematomas and hydrocephalus. The yield of such a procedure has been debated but probably lies somewhere between 1% and 10% and may even be lower.[25,26] Because Gifford *et al*.[27] showed that there is considerable uncertainty in the evidence underlying clinical prediction rules to identify which patients with dementia should undergo neuroimaging and the application of these rules may miss patients with potentially reversible causes of dementia, it is generally felt that a structural imaging investigation in the evaluation of a patient suspected of dementia should be performed routinely.

2. Magnetic resonance imaging

Magnetic resonance imaging (MRI) may be used for the same reason as CT but it has the ability to increase specificity to an already quite high sensitivity of the clinical diagnosis. MRI can show specific arguments in favor of AD, such as a volume reduction of the hippocampus which can be seen in the coronal sections. Hippocampal atrophy is an early and a rather specific marker of AD.

3. Single photon emission computed tomography and positron emission tomography

Single photon emission computed tomography (SPECT) and positron emission tomography (PET) are often used as a part of the work-up, especially in memory clinics and as a complement to structural imaging in difficult differential diagnostic questions.

Disclosure of Diagnosis

Of particular interest to specialist physicians are laws pertaining to the disclosure of diagnosis to the person him/herself rather than his/her family. Most European countries have not established the right to a diagnosis as an absolute right without exceptions and most legislation allows doctors to refrain from disclosing a diagnosis if this is considered to be in the ‘best interests’ of the person or if such disclosure could cause “serious harm” to the physical or mental health of the patient.[28] Nevertheless, a growing consensus has emerged[29] in favor of disclosing a diagnosis to the person at a time when the person is capable of understanding this. It has been shown that such disclosure relieves the anxiety of uncertainty and maximizes individual autonomy and choice by providing the information necessary for decision-making and advance planning,[30] including the decision to give informed consent to research projects and autopsy. In any case, disclosure of diagnosis should be done tactfully and should be accompanied by information about the consequences and the progression of the disease, as well as useful contacts such as the local or national Alzheimer's association. In countries where this is possible physicians may also wish to encourage patients to draw up advance directives containing future treatment and care preferences.

B. The New Diagnostic Framework of AD

Based on the original NINCDS-ADRDA criteria,[31] the diagnosis of probable AD requires a two-step procedure. Firstly, a dementia syndrome must be invoked by clinical examination, documented by mental status questionnaire, and confirmed by neuropsychological testing: there must be deficit in two or more areas of cognition, including memory with a progressive worsening over time responsible for a significant impact on the activities of daily living. Secondly, a process of exclusion should rule out other possible etiologies of a dementia syndrome with blood investigations, brain neuroimaging, and, where appropriate, additional investigations such as CSF examination.

Considering AD only as a "dementia" has obvious limitations, the most obvious being that it precludes diagnosis of patients with early memory problems. AD pathology is already well advanced by the time patients present with their first cognitive symptoms, even if these are not sufficient to meet current criteria for dementia. Earlier diagnosis may allow for earlier therapeutic interventions. In addition, the NINCDS-ADRDA criteria are not only late but they have a low performance[32] because at the time (1984) no reference to biomarkers was proposed. Biomarkers for AD are now available at least in expert centers. These biomarkers can be divided into those that can demonstrate facets of the underlying pathophysiology, and those that are topographical/downstream markers,[33,34,35]

The reliable identification of biomarkers of AD has been responsible for a major change in the conceptualization and diagnosis of the disease. Importantly, the new diagnostic criteria proposed by the International Working Group (IWG)[36] and latterly by the NIA/Alzheimer's Association (NIA/AA)[37] both now use paraclinical investigations (MRI, CSF), not only for excluding other etiologies of a dementia syndrome but as part of the diagnostic procedure.

Considering biomarkers not to be linked to a stage of severity but rather to the disease process, these criteria potentially allow identification of Alzheimer's disease at a *prodromal* (= predementia) stage and even at a *preclinical stage* (= without symptoms) of the disease. Both sets of criteria recognize preclinical states of AD that are necessarily based on pathophysiological biomarkers since cognition remains normal. The IWG/Dubois criteria identify these individuals as "asymptomatic at risk for AD". This neutral nomenclature was chosen to acknowledge that not all these individuals progress to symptomatic AD. The NIA/AA criteria describe this state as "preclinical AD". This nomenclature may have more of an implication for progression, suggesting that "preclinical" is the predecessor state for "clinical" AD. ■

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3.2 Alzheimer's Disease: Rehabilitation Treatment

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Alzheimer's disease (AD) is the principal cause of dementia and is also one of the most devastating and prevalent chronic pathologies amongst elderly people. As was indicated in the report by the World Health Organisation and Alzheimer's Disease International, in 2010 it was estimated that over thirty-five million people had dementia in the world, of whom more than a half had AD, and it was estimated that there was an increase of 7,700,000 cases every year – one new case every four seconds. The incidence of dementia increases with age and given the progressive ageing of the population the number of individuals tends to increase every year. Indeed, it is calculated that there will be 65.7 million dementia patients in the year 2030 and 115.4 million in 2050. In the same report of 2010, the annual cost of dementia in the whole world was $US 604,000,000,000 – about 1% of world GDP. Such a high cost testifies to the enormous impact of dementia on socio-economic conditions throughout the world. It is estimated that in Italy there are more than a million people with dementia, with an increase of 150,000 new cases every year. It is calculated that about 700,000 people have AD, with about 800,000 new cases every year – one new case every ten minutes. In Lazio, in 2012, it was estimated that about 71,000 people had dementia, of whom 28,000 had AD. The incidence for all forms of dementia, applied to the part of the population resident in Lazio over the age of sixty-five, is about 14,000 new cases every year.

In clinical terms, Alzheimer's disease is characterised by a progressive cognitive and functional deterioration and by forms of mental and behavioural disturbance. From the appearance of symptoms until death, five to fifteen years can pass; the characteristic histopathological lesions of this pathology are said to precede by as many as twenty years their actual clinical manifestations. People afflicted by this pathology develop increasing cognitive and functional, mental and behavioural, disturbances, and during the final stages of the disease they become completely dependent on other people for their survival. Whereas it is possible to describe the symptoms that generally accompany the advance of this disease, it is not possible to predict when a specific symptom will be manifested in a given individual or how much time will pass before the symptom disappears or when the disease will get worse. The aetiology of AD involves many factors, the physiopathology of the disease is complex and its biochemistry has still not been understood.

Alzheimer's disease has been identified as a pathology of protein 'misfolding', with the accumulation of the amyloid beta protein which is 'misfolded' in an altered way in the brains of these individuals. Amyloid beta (Aβ) is a short peptide that is an abnormal proteolytical sub-product of a transmembrane protein known as the amyloid precursor protein (APP) whose functions is still not clear but which, it is thought, can be involved in neuronal development. The monomers of amyloid beta are soluble but at a sufficiently high concentration they undergo a dramatic conformational change and aggregate to form amyloid fibrils. These deposits of fibrils are located outside the neurons in dense formations which are known as (amyloid or neuritic) 'senile plaques' and in less dense aggregations as 'diffuse plaques'. At times they are to be found in the muscular walls of the blood vessels, giving rise to what is termed 'amyloid' or congophilic' angiopathy (because the amyloid substance has the strong colour of Congo red).

Alzheimer's disease is also seen as a 'tauopathy' because it is caused by an abnormal aggregation of the tau protein, a protein that is associated with the microtubules present in the neurons which normally act to stabilise the microtubules of the cytoskeleton . Like most proteins associated with microtubules, the 'tau' is normally stabilised by phosphorylation. However, in patients with AD it accumulates with paired helicoidal filaments of hyper-phosphorylated tau which in their turn aggregate in clusters inside the bodies of the nerve cells and are known as 'neurofibril nodes'.

Neuroinflammation is also involved in the complex cascade that leads to the symptoms of AD. A great deal of clinical and neuropathological evidence documents the immunological changes associated with Alzheimer's disease, amongst which we may observe an increase in the concentrations of pre-inflammatory cytokines in the blood and in the cerebral-spinal liquid. Whether these changes can be a cause or a consequence of AD still has to be fully understood but the inflammation inside the brain, including a greater reactivity of the resident microglia to the amyloid deposits, has been implicated in the pathogenesis and the progression of this pathology.

Amongst the principal hypotheses advanced as regards the primary cause of AD, the oldest hypothesis suggests that a cholinergic lack sets in motion the advance of the disease.

More recent hypotheses have focused on the effects of the 'misfolding' and aggregate proteins – amyloid-beta and tau. In a scientific publication the two points of view have been described as hypotheses of the 'Ba-ptists' and the 'Tau-ists'. In practice, the 'Tau-ists' believe that it is the anomalies of the tau protein that set in motion the disease whereas the 'Ba-ptists' believe that the causal factor of the disease is the deposits of amyloid-beta.

These changes could cause the death of neurons, initially in the hippocampus and then gradually in other areas of the brain. The neurons lost during the advance of the illness are principally cholinergic (they use acetylcholine as a neurotransmitter) and thus the cognitive disturbances that as a rule are the first symptoms in the manifestation of the disease have been attributed to its reduction. In conformity with these observations, researchers developed pharmaceuticals that increase the levels of acetylcholine (acetylcholinesterase inhibitors) or are useful in slowing down the death of cells (memantine).

Acetylcholinesterase inhibitors and memantine are the only medical products that are now approved for AD. The latest pharmaceutical approved by the Food and Drug Administration (FDA) for the treatment of Alzheimer's was memantine in 2003. The benefits for patients treated with one of these medical products (some are treated with a combination of acetylcholinesterase inhibitors and memantine) are not satisfactory. These are only compensatory pharmaceuticals and thus symptomatic and do not modify the disease. Indeed, they can only offer a limited relief from clinical symptoms and on the average they delay cognitive decline by only six to twelve months. The majority of current studies focus instead on the search for molecules that can change the evolution of this disease, blocking the production of amyloid plaques and the formation of neurofibril nodes.

Given the current absence of therapies that can modify the presumed pathogenesis of AD, the scientific community has been stimulated to explore the efficacy of rehabilitation treatment to manage the manifestations of this dementia syndrome with the aim of delaying cognitive and functional decline, reducing psychological and behavioural disturbances, and thereby improving the quality of life of patients and their families.

The conceptual base to support this rehabilitation treatment is supported but two peculiarities of the nervous tissue: neuroplasticity and cellular redundancy (functional reserve). Indeed, recent scientific evidence has demonstrated that the brain, during old age as well, has the capacity to re-adapt and reorganise its own microstructure (plasticity) by restoring connections between neurons and thereby retrieving, partly or totally, functions that have been lost. The most immediate example for an understanding of this 'plasticity' of the nerve cells is the retrieval of movement functions or language functions which can take place after an acute cerebral event (ischemic ictus).

The data of the literature in the field suggest the existence of *four principal types of neuroplasticity* in the adult brain following cerebral lesions: the *expansion* in the representation maps (as takes place, for example, in the study of a musical instrument such as the violin); *cross-modal reassigning* (people blind from birth demonstrate activity of the visual cortex – '*they see*' – when they use touch reading); the *adaptation of areas similar to those that have been injured* (retrieval of language through activation of areas near the lesion or similar areas of the non-dominant hemisphere); and *masked compensation* (an intact cognitive system substitutes the functions of the injured system by adopting new cognitive strategies to carry out the function that has been lost).

Both in animals and in man it is thus possible to obtain the reorganisation and adaptation of cerebral representations both spontaneously and following important cerebral lesions through adequate stimulations. The data of the literature in the field which concern these modes of cerebral reorganisation and compensation in patients with dementia remain, however, limited.

In a study carried out with the methodology of trans-cranial magnetic stimulation connected with the excitability of the motorial cortex in patients with Alzheimer's disease, there was a demonstration *of the presence of a reorganisation of the motorial cortex as early as the first stages of the disease*. This interesting work confirms the clinical evidence that describes the appearance of motorial deficits only during the advanced stages of this disease.

The other column that supports the scientific basis of rehabilitation treatment in individuals with dementia is redundancy by which every function can be carried out by more than one neuronal circuit as a result of which if the principal circuit is damaged it can be replaced by accessory circuits which constitute a sort of natural resource (functional reserve) of the brain.

Lastly, to give further support to the rationality of rehabilitation treatment in the case of Alzheimer's disease, there are studies that have highlighted that in AD the cognitive functions are not damaged in a homogenous way from the onset of the disease but, rather, follow a pattern of progressive impoverishment (hierarchical progression). Indeed, at the onset of the disease it is episodic memory (explicit memory) that suffers a deficit, whereas other cognitive functions are relatively spared (language, movements, agnosias). In addition the (procedural) implicit memory remains conserved longer than the explicit memory, and what remains of the latter, during the very early stages of the disease, can be rehabilitated with special techniques. People with Alzheimer's disease are thus able to learn or re-learn.

These advances, the limited efficacy of forms of pharmacological treatment, which today are substantially symptomatic, and the appearance in the scientific literature in the field of data which point to a combined (pharmacological-rehabilitative) approach as being better than mere pharmacological treatment, have helped to reduce the prejudicial scepticism as regards the utility of rehabilitation treatment for these patients and have led many research groups to engage in experimentation in this direction.

However, it appears evident that the aim of these forms of cognitive and functional rehabilitation treatment for a patient with Alzheimer's disease cannot be that of '*restitutio ad integrum*' and this is because of the progressive degenerative nature of the disease. But it is certainly that of maximising the capacity to maintain the functional autonomies of the patient in his or her own environment with the limitations imposed by the disease, by the functional damage and by the resources that are available. The definition of the World Health Organisation lays down that: 'Rehabilitation must involve patients so as to bring them back to the highest obtainable level of physical, psychological and social adaptation; rehabilitation treatment must therefore include all measures that seek to reduce the impact of the disability and handicap and allow the patient to obtain the greatest functional autonomy, in particular in his or her home environment'.

Starting with these observations, one can state that it is specifically patients with dementia syndromes who become *some the greatest beneficiaries of rehabilitation treatment*.

Helping a sick person to remain in the best conditions for the longest time possible, through rehabilitation strategies and psychosocial measures as well, becomes a concrete goal of ethical, economic and moral success while we await new medical products that can act on the mechanisms that set in motion Alzheimer's disease.

The concept of 'rehabilitation' applied to a patient suffering from AD thus acquires a very *broad and complex (holistic) meaning* because of the cognitive, functional and behavioural *domains* where action has to be taken and because of the *socio-environmental and relational contexts* that have to be taken into account.

For these reasons, the rehabilitation approach must envisage measures which, taking into account the socio-familial context and functional resources of the patient, make the physical and personal environment of the patient such as to *promote a new adaptive equilibrium*.

This requires the development of rehabilitation actions *in relation to the individual* (which seek to achieve a cognitive, functional, psychological and behavioural compensation), *to the environment* (in order to construct a new adaptive and prosthetic balance), and *to the family* (involving psychological and educational support so as to transmit skills and expertise as regards the disease, the resources of the local area, legal questions, etc.), whose *final objective* should be to identify the best strategies by which *to strengthen the cognitive and functional abilities of the patient or slow down their loss*, *control his or her mental and behavioural disturbances* and thereby assure *the best quality of life* for that patient and his or her family in relation to the clinical and socio-environmental situation (bio-psycho-social rehabilitation).

Compared to pharmacological therapies, these forms of treatment require a greater commitment, continuity and the active participation, as well, of those who take care of the sick person in planning, programming and applying the rehabilitative actions.

If we wanted to provide a schematic description of forms of rehabilitation treatment, we would sub-divide them into 'direct' forms of treatment, which are carried out on the sick person himself or herself, and 'indirect' forms of treatment, when action is taken in relation to the family and the environment in which the patient lives.

Direct rehabilitation measures can be then divided into *mono-strategic ones and multi-strategic ones*; *indirect* rehabilitation measures involve *psycho-educational and environmental* actions.

Mono-strategic and multi-strategic rehabilitation treatment

Mono-strategic rehabilitation measures (cognitive mnemotechniques and training) seek to stimulate as a priority certain cognitive processes and for these to produce results their relative conservation is required. They are based upon techniques that stimulate specific mnemic processes which during the initial stages of Alzheimer's disease are only partly compromised and require an active cooperation on the part of the patient.

Mono-strategic techniques are thus specifically directed towards the processes of memorisation, which are initially altered by AD. Some have been developed with aim of facilitating the *codification* process such as the *learning without errors technique and the technique of visual images*; others have been developed in order to improve the patient's capacity for recall, for example the *technique of recall at growing intervals and the technique of decreasing facilitations*. Yet other techniques have been developed to provide help both to *codification* and to the stages of *recalling* what has been learnt, such as the *codification specificity strategy with cognitive facilitation* for the recovery of episodic memory.

Mono-strategic techniques use two different rehabilitation strategies: repairing (or restoring) strategies or compensatory strategies.

The aim of repairing (or restoring) measures is to improve the functioning of a specific domain, returning the cognitive function to pre-disease levels. To the category of restoring measures belong: *the technique of recall at growing intervals; the method of decreasing and increasing facilitations; the technique of learning without errors; and training in procedural memory (sense-motorial stimulation)*. These techniques also include re-orientation therapy and reminiscence therapy which, however, also seek to improve temporal, local and personal orientation.

The objective of compensatory measures is to teach patients who have cognitive decline new ways by which to engage in activities that have been compromised (for example those of everyday life) by using alterative strategies to by-pass cognitive deficits which impede their performance. This approach lays stress on the use of internal strategies (mnemotechniques) such as the organisation of information that has to be remembered or the improvement of the codification of information through more than one sense pathways, such as sight and hearing, but it also includes the use of external aids and the stimulation of the procedural memory in the patient.

Compensatory measures, therefore, concentrate on the stimulation both of the cognitive mechanisms which have a deficit (the codification, storing and recall of information) and of the cognitive functions that are still whole (procedural memory). The following techniques belong to compensatory strategies: *visual images, aids for the external memory* such as notebooks, calendars, alarms and neuropage, and the *dyadic approach* (educating the caregiver in utilising the various strategies in order to improve the cognitive functions of the person they are looking after).

The data of the literature in the field demonstrate that *the technique of learning without errors, the technique of recall at growing intervals, the technique of decreasing facilitations and the dyadic approach*, used on their own or in combination, are effective in the stimulation of the memories of patients suffering from Alzheimer's disease.

These two ways of acting (compensatory and restoring) can be utilised together or can be part of a broad programme of multi-dimensional rehabilitation which also envisages multi-strategic, psycho-social and environmental measures.

Multi-strategic rehabilitation measures are also called 'aspecific' or 'global' because they stimulate the internal (cognitive and emotional) and external mechanisms that intervene in the learning process. They can be used both individually and with small groups of patients which are as homogenous as possible as regards the type and gravity of the disturbance that is suffered from. Controlled clinical studies have demonstrated the efficacy of these techniques and not only in relation to the cognitive aspects of the malady. Below those most frequently cited in the literature in the field will be described.

These measures, also using not specifically cognitive but prevalently *emotional and environ-*

mental resources, still produce positive results with reduced cognitive resources. With the progressive compromising of the cognitive processes, although mono-strategic measures can be used increasingly used, the use of multi-strategic rehabilitation measures find increasing space.

The data of the literature in the field have also demonstrated that a (multidimensional) rehabilitation approach on more than one deficit area has better results than rehabilitation measures applied to a single deficit.

Indirect rehabilitation measures: psycho-educational treatment

Family relatives have an essential role to play in the provision of care to patients with Alzheimer's disease, 80% of whom live in their own homes and far too often do not have a reference point to which to turn in their state of need. It is thus important to involve family relatives, together with the caregivers, in the rehabilitation project and support them with suitable training and psychological support. In a recent assessment of the efficacy of rehabilitation measures carried out by Olarazan and colleagues, in the 179 random control studies that were examined, the highest level of effect (grade A) was achieved specifically through 'packets' of psycho-educational measures for family relatives and caregivers, which were shown to be useful in improving psychological wellbeing and delaying the institutionalisation of the patient.

Indirect rehabilitation measures: the environmental (compensatory prostheses)

The cognitive deficits that develop during the course of dementia cause increasing difficulties in recognising and using domestic environments as well: this can provoke the appearance, or amplify the intensity of, mental or behavioural disturbances, with negative consequences for residual functional abilities and the quality of life of the patient and his or her family. Every rehabilitation measure that seeks to offer adequate care to an individual with dementia has to take account of these difficulties and has to take into account the process of acting on the physical environment, adapting it to the resources of the sick person.

The adaptation of environments has to take into account both the cognitive deficit of the patient and the presence of sense disturbances (sight, hearing or movement) that are correlated with the pathology or specific to his or her age, such as slowing down or instability in walking, presbyopia, less capacity to adapt to the dark, a vulnerability to phenomena involving errors of perception, the loss of peripheral vision, and presbycusis.

Lastly, the presence of other concomitant pathologies of the organism that can provoke pain or other sense deficits should also be assessed.

In order to compensate for the difficulties that can derive from the deficits that have been described and make the domestic spaces suitable to being used by the patient, one should actuate specific compensatory ('*prosthetic*') rehabilitation measures. These compensatory measures should be such as to guarantee the greatest safety without reducing the freedom and the autonomy of the patient. They should foster a topographical and temporal orientation, the maintenance of personal and familial identity, and avoid the appearance of mental and behavioural disturbances.

In order to guarantee safety, the exit routes (windows, doors, balconies, gardens, terraces, floors and stairs) should be tested as well as other sources of danger (electric home appliances, lights, various kinds of equipment and utensils, medical products, disinfectants and detergents, plants, windows and window panes) so as to educe to a minimum the risk of flight, falls, injuries, accidental burning and electrocution, and the ingestion of poisonous substances. It is also useful to cover spikes, sharp edges and walls with soft materials in order to reduce the risk of accidental injuries.

In order to foster spatial orientation, one can use visual facilitations (for example a drawing of a WC on the door of the bathroom), assure suitable lighting, and simplify access day and night to home environments (for example placing the bed near to the bathroom if the individual involved is still able to use it but gets lost on the way, and leaving a night light so that it can be reached).

To facilitate temporal orientation one can place calendars and clocks that are very visible and easy to read in the various environments of the home.

To conserve autonomies for as long as possible, the environments have to be gradually adapted to the cognitive capacities of the patient. For example by making *objects that are still recognised and used very visible* (make the WC evident by covering the bidet and by placing utensils that are still used always in the same place) or by equipping the kitchen with electric rings or gas metres if he or she is still able to use the kitchen (rather than impeding him or her from cooking) or facilitating reaching the bathroom (written signposts or drawings) rather than accompanying him or her.

To foster the control of behavioural disturbances, one can create a privileged space for rest where the patient can go or where he or she can engage in activity dealing with handling (a chest in which he or she can look through things) or relax (a soft corner), eliminating all the objects that can be destroyed (vases, things on furniture, plants) or lost (keys), and covering objects that can cause illusory phenomena or hallucinations (the TV, mirrors, reflecting surfaces).

Conclusions

The scientific literature in the field of the last decades has provided increasingly robust evidence about the validity of rehabilitation activity to improve or slow down functional or cognitive deficits and the efficacy of psycho-social measures in the control of mental and behavioural disturbances which manifest themselves during the course of the illness and of the quality of life of the patient and the caregiver.

In many European guidelines rehabilitation and psycho-social measures are recommended and in particular it is recommended that pharmacological therapy should not be begun for mental and behavioural disturbances without a prior rehabilitation and psycho-social action to correct the possible psychological or social causes that may underlie them, and this after first excluding, obviously enough, possible physical causes.

Bio-psycho-social integrated rehabilitation action which takes into account the patient as a whole and the environment that surrounds him or her, seems thus to be the most appropriate approach in managing the needs of this pathological condition which must have suitable treatment in the place where the patient lives or is cared for (day centres, rehabilitation and hospital institutions, health-care homes).

Rehabilitation measures can be applied both individually and in small groups with patients that are as homogenous as possible as regards the type and the gravity of their deficit. Both these approaches have a greater probability of being effective if they are integrated into a more complete plan of action made up of many components which involves, linked to the level of gravity of the illness, physical activity, therapies for symptoms (as regards cognitive deficits and/or psycho-behavioural disturbances if they are of a high level of gravity and the rehabilitation measures on their own have not been effective), and psycho-educational measures for the patient, the caregiver and the family.

However not all rehabilitation measures have found solid support and definitive indications that are rigorously based upon controlled random clinical studies.

But their broad diffusion, the familiarity of health-care workers with these approaches and the positive results, often obtained empirically in a few cases, however, supports their clinical use and opens up the field to a *vast territory of research* closely linked to practice, of which there is a great need.

As a consequence, it has become increasingly urgent to set in motion specific projects of research which have a number of centres and which will allow us to have a better understanding of the utility and limits of rehabilitation measures as regards degenerative diseases; to define in a better way the methods of action, which are still heterogeneous and not well codified; to identify efficient measures which are sufficiently sensitive to grasp the meaning of wellbeing as referred to the patient/caregiver and to engage in an analysis of predictive variables in order to determine in a precise way which rehabilitation treatment is best adapted to each typology of patient in order to maximise the benefits, to assess the effectiveness in the long term, to develop global/holistic rehabilitation measures, to analyse the cost/benefit ratios, and how much the measures can be generalised.

While awaiting the setting in motion of these projects one can only continue to stimulate the spread of an integrated social/health-care approach that can assure, in addition to pharmacological therapy, a continuity of rehabilitation actions for the patient, for his or her family, and for the environment that surrounds him or her, guaranteeing: increasingly 'tailored' and multidimensional actions that actively involve the sick person and the caregiver; their continuity during the various stages of the illness and in the different places of care; training and psychological support for and supervision of the family relatives and the health-care workers; and the development of guidelines and operational textbooks.

To complete what has been said hitherto, in the next sections of this article I will describe, in general terms, the principal rehabilitation mono-strategic and multi-strategic approaches to which I have referred so far in this work and which are used most frequently for these patients.

Mono-strategic Approaches (Menemotechniques and Cognitive Training)

Mnemotechniqes: tricks and strategies to help the memory

Mnemotechnniques are techniques that are *used knowingly* to improve memorisation. They help in the using of information that is already present in the long-term memory in order to make the learning of new data easier. Together with cognitive training, they form a part of the rehabilitation methods used in individuals with a slight cognitive impairment.

This term is also used to indicate compensatory strategies and tricks to help patients to memorise new information, that is to say to allow the mind to learn a new notion or a notion that is relatively unfamiliar, and above all a series of dissociated data, connecting them in a singular way and in a way that makes their memorisation and recall easy.

These strategies have the aim of working through the information in a form that the human brain can retain in a better way than its original form; they help the person to *retain and remember* information that has already been acquired by the long-term memory, facilitating, thereby, its memorisation.

These strategies can help both the learning process and the *transfer* of information to the long-term memory.

It commonly happens that the mnemotechniques used to memorise and remember *number sequences or lists of words* are of a hearing kind, for example short poems, acronyms or striking phrases, but mnemonic tricks can also be used to memorise other kinds of information, for example visual information or kinesic information.

The most used mnemotechnique utilised to memorise lists is that of creating an acronym that is easy to remember, taking each of the initial letters of the list of words that have to be learnt, or creating an unforgettable phrase whose words begin with the same letters of the acronym. Anyone can create their own mnemonics to help in the memorisation of new notions.

To memorise the colours of the rainbow in their own order one can use the invented name 'Roy G. Biv' or the phrase 'Richard Of York Gave Battle In Vain' – each one of the initial letters of the name or the phrase corresponds to the colours of the rainbow in their order (Red, Orange, Yellow, Green, Blue, Indigo, Violet).

Mnemonics can use *internal* strategies (*mental* mnemonics) and/or *external* strategies (prostheses, aids).

The most frequently used mental mnemonics (which are also defined as '*internal cognitive prostheses*') are of a verbal, visual, auditory, or kinesic and associative kind, or are related to places (*loci*).

The external strategies can be *active or passive*; the 'active' mnemonics that are used most frequently are diaries, calendars, timers, blackboards, lists, alarms, computers and neuropages (radio/bleeper systems that send out reminders) and so forth. 'Passive' mnemonics are seen as environmental adaptations (cognitive and functional aides, protection and security systems). They are also defined as '*external cognitive prostheses*' because they allow the stimulation of the memory. They are equipment which allows the organisation and management of time, improves attention, provides directions, reduces the cognitive requirements and stimulates the patient as regards the events of his or her daily life. The most common internal and external mnemotechniques will now be listed.

INTERNAL MNEMOTECHNIQUES

Verbal techniques

Acronyms

Acronyms are formed by using each first letter of a group of words to produce a new word (for example USA = United States of America; IRC = Italian Red Cross). This is especially useful when one has to remember words in a particular order. Acronyms can be useful aids for the memory but they are useful only for the memory and not for an understanding of the material that one wants to learn. Acronyms can also be difficult to form and not all lists of words can be memorised with this technique. Lastly, it should be observed that acronyms can be forgotten if they are not learned by heart.

Acrostics/phrases

As with acronyms, the first letter of each word that one seeks to remember is used to form an acrostic. Rather than forming a new word it is possible to use the letters to form a phrase (*Viva V.E.R.D.I.: (Viva) Vittorio Emanuele Re D'Italia; 'Ma con gran pena le reca giù*' used to memorise the order of the Alps: '*Ma*rittime, *Co*zie, *Gra*ie, *Pen*nine, *Le*pontine, *Re*tiche, *Car*niche, *Giu*lie). Acrostics can be very simple to remember and are particularly useful when one has to remember a list in a particular order, but they need a greater effort to be created and require the memorisation of an entire phrase rather than a single word.

Rhymes/melodies-songs

Rhythms, repetitions, melodies and rhymes can help in memorisation. Narrators use rhyme, rhythm and repetition in order to remember stories. Rhymes and songs stimulate the auditory memory and can be particularly useful in learning passages, poems or songs easily. In this case as well, rhymes and songs highlight the mechanical role of the memory.

Sub-division into blocks/groups

This technique is generally used to remember numbers, even though it can be used to remember certain things. It is based on the idea that the short-term memory is limited as regards the number of elements that it can contain. A common rule is that a person can remember 5-9 elements at a time (for example a telephone number made up of seven numbers). When one uses a 'sub-division into blocks', one reduces the number of elements that have to be memorised, thereby reducing the size of each element (for example to remember the number 38965714, it is easier if one subdivides into blocks: 38.96.5714).

Visual and associative techniques

The loci method

This method was used by the ancient orators to remember speeches and combines the use of organisation, visual memory and association. Before using this technique, one has to identify a place or a pathway and it is essential to have a clear visual memory of the place or the pathway and the objects that can be found there. One has to imagine that one is walking along the pathway and to identify specific points of reference (for example a bedroom, a dining room, a familiar statue, etc.). The number of points of reference that are chosen depends on the number of things that one has to remember. Once the place or the pathway and the points of reference have been chosen, one has to associate mentally each piece of information that one has to remember with one of these points of reference.

The 'peg'/'hook' system of words

In this method, the words that have to be used are linked to individual mental images or put on 'pegs' (associations of numbers and words already learnt in a precise order). This strategy allows the recall of only ten words. One must first learn the rhyme: '*uno-pruno, due-bue, tre-re, quattro-gatti, cinque-pingue, sei-nei, sette-vette, otto-dotto, nove-piove, dieci-ceci*'. The noun must create interactive images to be connected with the words of the rhyme. This system is useful when something has to be learnt in an exact order. For example: '*child, book, milk, airplane*; => *a child* sitting under a *prune*, saw an *ox* with a *book* in its mouth, a *king* that drinks *milk*, *four cats* on an *airplane*.

Connections/associations

Rather than associating elements to be remembered with a ‘peg’, it is possible to associate them. This strategy of connections is used to remember everything that needs to be remembered in a sequence alone. In using concrete images, with the addition of colours, details and actions, one can remember this sequence: food shop, bread, milk and a hamburger. The food shop is visualised. Then you visualise yourself with bread in your mouth, then a photograph of a cow with a glass of milk and a hamburger tattooed in the neck or the stomach. Now, in activating these memories when going to do the shopping, it is possible to remember this sequence of things to buy by using the connected visualisations.

Auditory and kinesic techniques

Reading aloud

Reading aloud the material that has to be remembered is useful because in this way one stimulates the auditory or kinetic memory to learn. Reading aloud can help in the codification of information and to clarify complicated concepts and to understand what has been learnt.

Repetition

Repetition is another great help for the memory. For example there is the children’s game in Italy: ‘I went on a picnic and I took…’ With the addition of each new word, the preceding word is repeated. Often people can remember a large number of words in this way. Once one is able to remember five headings in a list of words, one should add a sixth, repeat the whole list from the beginning, then add a seventh, and so on.

Other internal mnemotechniques

Here one is dealing with *logical connections* (the formation of logical links between elements that have to be memorised); *semantic categorisation* (ordering the information within defined semantic categories); *phonological categorisation* (organising the information in conformity with phonological assonances); *schematisations* (learning is fostered through the schematisation of material); and the technique of *key words* which involves *two* stages: one is phonetic (semantic) and the other is visual. This a good technique by which to learn foreign languages and involves identifying a word that is phonetically similar to the foreign word that has to be learnt and in creating a mental image that establishes a connection between the meaning of the two words.

The PQ4R (or PQRS) method

The PQ4R (or PQRS) method amounts to*: preview* = preview, leaf through the text to be studied, identify chapters and subsections, read the illustrations and graphics; *questions* = pose questions about the contents; *read* = read it carefully trying to answer the questions that have been posed; *reflect* = reflect, relate the new knowledge with the knowledge that is already possessed; and recite = recite what has been read without looking at the text. If not enough has been remembered, take up the text again and repeat the parts of stages 2/3/4 where difficulties of recall have been encountered: *review or summarise* = go back over (or summarise) after reading a chapter, review it as a whole and recall the principal concepts that are expressed in it.

EXTERNAL MNEMOTECHNIQUES

For individuals who have Alzheimer’s disease it can be difficult to use strategies of internal memory and thus the use of external memory supports could become important. Some individuals during the early stage of AD frequently resort to the spontaneous use of simple aids as regards external memories, such as notes or calendars, which they use to remember important appointments or dates. In addition, most patients with Alzheimer’s disease increase their dependence on their caregivers as a form of external memory aid. In using external aids, however, one involves the memory, above all the meta-memory and the perspective memory, as well as certain executive functions, because the individuals involved must be aware of their memory problems and remember to record information, and how and when to access this information.

In order to overcome these difficulties, one can use ‘active’ technological aids, such as electronic equipment that produces audio messages and vibrations and which are worn by these people to remind them of the tasks that they have to perform (for example taking medical products, drinking and eating). Electronic equipment (dictaphones) can also be used to allow the individual involved to record messages on the things that he or she has to do or to remind him or her to ask his or her caregiver to do them.

Technological equipment can also be used to assure greater safety for the patient in his or her home (alarms for flooding, gas leaks, his or her attempts to go out, etc.).

Some advice to facilitate memorisation through internal mnemotechniques

- Using positive pleasurable images; the brain often blocks unpleasant ones.
- Exaggerating the size of important parts of the image (in order to make it enormous).
- Utilising a sense of humour. Amusing and special things are easier to remember than normal things. Similarly, rude or sexual rhymes are very difficult to forget.
- Utilising symbols (a traffic light that lights up, images on the person’s fingertips etc.)
- Creating vivid and coloured images which are easier to remember than grey ones.
- Utilising all the senses in order to memorise information or deck out an image; mnemonics can contain sounds, smells, tastes, touch, movements and sensations, as well as images, graphs, diagrams etc.
- Producing a three dimensional and moving image in order to make it more alive; and to maintain the flow of association and remember actions (make them move).

The important thing is that the mnemonic trick has to clearly refer to the things that has to be remembered, and it should be sufficiently clear to be easily remembered when it is thought about.

COGNITIVE TRAINING

Various cognitive actions have been developed to compensate for the deficits caused by an impairment of the memorisation processes (codification, storing, recall, etc.) that play a role in learning. In individuals who have Alzheimer's disease, disturbances of the memory seem to be caused principally by difficulties in the processes involving the *codification* and *acquisition* of new information, whereas the stages of storing and recall would appear to be relatively spared.

The objective of cognitive actions is to improve or support those functions that have been damaged so as to facilitate new learning; some techniques are also based upon the stimulation of areas that have not been damaged (for example the implicit memory).

When one speaks about actions relating to the cognitive functions in cases of people with Alzheimer's disease, terms such as 'training', 'rehabilitation' and 'cognitive stimulation' are often seen as synonyms in the literature in the field. Although training and cognitive rehabilitation are correlated, they are in fact two different forms of action, and both of them are separate from cognitive stimulation.

These approaches are complementary and the choice of a particular approach depends on the objectives as regards improvement or the maintenance of skills relating to knowledge and the profile of the cognitive state of the person who is being observed.

Cognitive training is a very specific approach which in general requires the teaching and the practice of repetitive standard exercises (with paper and pencil or with computers) in order to increase or maintain specific cognitive functions such as attention (verbal or visual memory) or problem-solving capacities (executive function), with a diverse gamut of difficulties in order to meet the diverse capacity levels of the individual involved.

Some authors have recently broadened the definition of cognitive training in order to include strategies that require the learning of techniques (for example the loci method, visual images) which where exercised have been demonstrated to be useful in slowing down cognitive decline.

Cognitive stimulation encourages the involvement of the individual in a series of amusing activities and discussions (usually in a group) which seek to achieve a general improvement in the cognitive and social performance of the patient, but without specific objectives. Normally, this takes place in small groups. Cognitive stimulation covers therapies such as *reality orientation therapy (ROT), validation therapy and reminiscence therapy*.

Cognitive rehabilitation is based upon the use of any strategy of action which identifies and addresses the needs of the individual with the objective of allowing patients and their families to manage cognitive deficits.

Cognitive rehabilitation involves therapies that have the aim of improving cognitive, perceptive and psycho-motorial deficits, reducing behavioural disturbances, and increasing levels of self-management and independence on the part of the patient

Cognitive rehabilitation envisages there being an *individualised intervention* that identifies personal objectives and the therapist works with the patient and his or her family to develop strategies by which these objectives can be attained.

Families are usually much more involved in cognitive rehabilitation and this is done in order to find strategies to achieve the objectives that have been established for or by the patient.

Stress is layed upon the improvement of performance in the activities of daily life rather than on cognitive tests in order to build upon the 'residual' resources of the person involved and to compensate the functional activities that have been compromised by the cognitive damage. A change obtained in a functional situation can not always be extended to another.

The objectives of cognitive rehabilitation are to improve the capacity of the patient and to work through and interpret information and to optimise his or her functional capacities for the performance of the activities of family life and community life.

Like mnemotechniques, *cognitive training* also uses compensatory and repairing (or restoring) strategies that act on the mechanisms of codification and the recall of data.

For the most part they are techniques to stimulate the explicit memory, whereas the implicit memory is stimulated through procedural memory training or sensory-motorial skills training.

Training for the Explicit Memory

Codification techniques (repairing or restoring techniques)

The technique of learning without errors fosters the elimination or the reduction of erroneous or inappropriate responses during cognitive training. In other words, by this approach people must not make mistakes when they are engaging in cognitive training. This technique aims to facilitate the acquisition of new information. The technique of learning without errors is used in association with the technique of recall at growing intervals or with the technique of decreasing facilitations. In the exercises of learning without errors people are taught to say that they do not know the answer rather than giving a wrong one. They are encouraged not to guess. Here is an example of this technique. The therapist says to the patient: 'I am about to teach you my telephone number: my number is 671.1369'. Then the therapist asks the patient: 'End what I tell you – my telephone number is 671.136. ..?'. If the patient answers correctly one goes forward in the exercise reducing the number of numbers that are repeated to the patient. The therapist then says: 'Good, my number is 671.13..?'. Things go on like this until the patient answers correctly. 'Good. My number is 671.1..?'. 'Good. My number is 671..?'. 'Good. My number is 67..?. 'Good, My number is 6..?. ' Good. My number is…? At this point the patient is distracted for a few seconds and then he or she is asked once again to repeat the number.

The techniques of visual (or absurd) images are based upon the concept that visual associations improve the codification, the consolidation and the capacity for recall of verbal material because the memory system is not only based upon the semantic verbal modality but also upon the visual one.

This (*compensatory*) technique is thus used to stimulate contemporaneously the modality of semantic and visual learning and to facilitate codification, consolidation and the capacity for recall of information in the patient's own environment. When new and unknown things are learnt, it is useful to associate them with anything that is known very well, for example images, word games, music, indeed anything at all. The association should not necessarily have a logical sense. Often it is especially vivid, entertaining or upsetting associations that remain most easily in the mind (for example if one has to remember the name 'Gabriele Verde', Gabriele should be visualised playing golf on the green, wearing green clothes or covered with green paint). Another example of a visual image is to ask the individual to form a mental image of an object that is presented verbally.

Recall techniques (repairing or restoring techniques)

The distance recall technique (or at growing intervals) involves the recall of the same information – for example face-name – at increasingly long intervals or with a growing number of intermediate elements. Rehabilitation measures that adopt this technique have been shown to be effective in the identification of objects, in face-name associations, in the spatial location of objects, and in the planning of daily activities (perspective memory). It is presumed that learning by this technique takes place above all else as a result of the procedural memory.

The technique of increasing or decreasing facilitations

This technique consists in making various attempts to remember a word (or data), steadily increasing (forward cueing) or reducing the letters that form it, until the recall is achieved successfully. This method is based essentially on two well defined and correlated principles: backward chaining and the conservation of the implicit memory. Some authors see this technique as a complementary strategy to allow training in learning without mistakes. An example of this technique is as follows: the word 'Piatto' is first shown, then 'Piatt-' and then 'Piat-' and so forth. The patient is asked to read it and to recognise it as the letters are reduced.

Techniques involving the facilitation of codification and recall

The technique of codification specificity with recall support is a strategy that is utilised to support codification and recall episodic learning. The technique of codification specificity requires the use of indications that are similar to those of acquisition (or codification) and recall inasmuch as the quantity of superimposition of information between a signal presented for recall and the representation of memory established for codification is fundamental in the task of episodic memory.

The *dyadic approach* is an action of '*compensatory*' training where it is the caregiver, family relative or partner, or rather the dyadic relationship that is created with the patient, that becomes decisive for the implementation of different (mono- or multi-strategic) rehabilitation programmes, rather than the type of action that is used.

Implicit (or Procedural) Memory Training

Procedural memory training (sensorial-motorial skills training).

This training is used to stimulate the carrying out of special types of action which can be accessed and used without the need for conscious control or attention. When necessary, the procedural memories are, in fact, automatically recalled and used for the carrying out of the procedures involved in cognitive functions and motorial abilities, for example tying a shoe, piloting an aeroplane, swimming, skiing or playing tennis. The procedural memory is a long-term memory and more in particular it is an implicit kind of memory that is created through 'procedural learning', that is to say by repeating a complex activity repeatedly until all the related neural systems work together to produce the activity involved in an automatic way. Procedural, or implicit, learning is essential in the development of any motorial ability or cognitive activity. There is evidence that procedural learning is relatively well maintained in situations of Alzheimer's disease.

This technique, which consists essentially in the breaking down of a complex action in simple acts which are concatenated with each other in a logical sequence has been demonstrated to be useful above all in patients with light-medium dementia but who are without associated behavioural disturbances. Comforting results have also been obtained when this technique has been used in patients with cognitive impairment of a high level. This '*restoring*' treatment has as its objective that of supporting and increasing procedural learning by involving the patient in instrumental activities and the basic activities of his or her daily life.

This technique can be taught to the family as well so that it can then use it in order to stimulate its sick relative. During a session of procedural memory training (PMT), to the patient can be offered exercises involving stimulation or the carrying out of activities in order to improve communication with the external world (for example sending a letter, using a mobile telephone, etc.) or activities to improve the quality of life of the person in question (such as looking after personal hygiene, making coffee or a baking cake, putting on an article of clothing, etc.).

Cognitive training programmes and mnemonics can be used individually or in combined fashion. They can be used for different purposes: to facilitate the recall of the relevant events of life, to improve the working of the memory, to improve the executive functioning through problem-solving exercises, and to increase social interaction by improving communication capacities, through specific conversation exercises, as well, so as to improve verbal fluidity.

MULTI-STRATEGIC APPROACHES

Multi-strategic rehabilitation techniques produce positive results both in relation to cognitive disturbances and with respect to mental and behavioural disturbances of patients with Alzheimer's disease, with a positive impact on their quality of life and their families. Those that are most used will now be described.

Re-orientation therapy (ROT)

Re-orientation therapy (ROT) was created by Folsom in 1958 at the Veterans' Administration (Topeka, Kansas) for war veterans and it was then developed in the 1960s as rehabilitation specifically for confused patients or patients with cognitive deterioration. Of the multi-strategic/psycho-social rehabilitation methods, this is the one that is most widely used. This technique seeks to re-orientate the patient towards himself or herself, towards his or her history, towards the surrounding environment, and also to increase the person's level of attention, participation in the life environment and adherence to reality.

The most suitable candidates for ROT are patients with light to moderate cognitive decline, with sufficiently conserved language, and with relevant sense deficits or behavioural disturbances that can influence participation in the rehabilitation sessions. This technique involves rehabilitation activity and can be engaged in individually or in small groups. There are two kinds of ROT: formal ROT and informal ROT.

Formal ROT is carried out in daily sessions which last about forty-five minutes. It can be individually provided or practised in a group (4-5 people who are homogenous as regards their level of cognitive deterioration).

After listening to the patients and creating a cordial atmosphere, the cognitive rehabilitation session begins. During this session a methodology of standardised stimulation is employed and this is directed towards re-orientating the patient as regards time, his or her own person, space (for example remembering his or her address, the neighbourhood he or she lives in, etc.) and the environment (for example his or her domestic environment if it is carried out at home). The multi-modal (verbal, visual, written or musical) stimulations have to be suited to the cognitive resources of the patient involved.

Informal ROT, on the other hand, envisages a process of continual stimulation that is not standardised and lasts the whole day by those who care for the patient (health-care workers and family relatives). These figures, during their contacts with the patient, provide him or her with repeated information. In the case of informal ROT this is carried out in the life environment of the patient and in addition he or she is provided with temporal-spatial facilitations (calendars, photographs, or icons to identify the rooms or written signs that are clearly legible) which act as environmental mnesic prostheses (external aids). An association of the two forms of action has been shown to be more effective. Greater advantages can be obtained by adding to ROT other rehabilitation techniques such as, for example, reminiscence and re-motivation therapy: thereby configuring the techniques that is also called 3R therapy; ROT can also be flanked by procedural memory training, by motorial rehabilitation, or it can be associated with occupational therapy.

The objectives of this rehabilitation technique are to re-orientate the patient as regards his or her identity, time and space (stimulating him or her to remember, for example, his or her date of birth, and the time and space in which he or she finds himself or herself) and to stimulate his or her memory by involving him or her in subjects connected with his or her personal history. As regards this last aspect ROT is seen as a cognitive-behavioural rehabilitation technique because it involves affective aspects of the patient that are correlated with his or her emotional life, with the evident positive value that this involves as regards the stimulation of his or her cognitive functions.

In particular, group ROT leads the patient to be involved in meaningful social relationships that are useful in improving his or her level of self-esteem, reducing a tendency to isolation in which these kinds of patients often find themselves, and modifying maladjusted forms of behaviour that they display.

Reminiscence therapy

This therapy was developed by Dr. R. Bluter in the United States of America in the 1960s and was called 'live review'. It is a method directed towards patients with light to moderate cognitive disturbances that are not associated with behavioural disturbances.

Reminiscence theory can be used in an informal or a formal way, located within structured encounters. It can be individual therapy or group therapy.

Reminiscence therapy is a technique that uses the remote events of the life of a patient as a point of departure in order to stimulate the residual mnesic resources and to retrieve emotionally pleasant experiences.

In the literature in the field it is referred to as life review, oral history, autobiography, family folklore, family stories and milestone therapy; despite different shadings these terms, because of the shared objective that they set themselves, may bee seen as being synonyms

Reminiscence therapy or life review therapy is based, therefore, upon the natural tendency of an elderly person to evoke his or her own past; memories and nostalgia can be a source of satisfaction and idealisation. The objective is to foster this spontaneous process and make it more aware.

During the meetings of this therapy the therapist, therefore, stimulates the patient to remember episodes from his or her life, above all the most remote ones. In order to facilitate the recall of ancient memories, the therapist can use old books, images, photographs and songs.

The health-care worker must stimulate the recall of pleasant memories and maintain the conversation within the limits of the cognitive possibilities of the patients but without ever provoking frustrations due to questions or subjects that are too difficult to follow. He or she, in addition, has to counter the recall of negative memories.

Reminiscence therapy is said to be 'failure proof' because the patient, usually, feels secure if he or she has to recall episodes from his or her past life, whereas he or she would be embarrassed to be asked what he or she had eaten for lunch or to say what day of the week it was.

Reminiscence therapy thus allows sick people to maintain their own self-esteem intact, indeed to increase it when they are still able to remember, rather than to frustrate it by concentrating on what they cannot remember because of their pathology. The patient in this way finds reasons for gratification that can correct maladjusted behavioural reactions and facilitate relational exchanges.

Reminiscence therapy can be flanked in a complementary way by other structured methods such as re-orientation therapy (ROT)

3R therapy

This is cognitive-behavioural global reactivation that is based upon the combined use of three stimulation techniques (ROT, reminiscence therapy and re-motivation therapy) relating to the cognitive-behavioural resources of the patient. It is for patients with medium-light levels of dementia and where there is an absence of behavioural disturbances and sense deficits. It has three objectives: *reorientation*: through stimulations connected with space and time, using ROT, it seeks to help the patient to rediscover environmental points of reference; *reminiscence*: stimulating the mnesic resources to recall pleasant events of the past through autobiographical experiences; and *re-motivation*: through the discussion of certain subjects connected with the current life of the sick person, thus making that individual feel more a participant and re-motivated in his or her life context.

Occupational therapy (OT) – 'ergotherapy'

Occupational therapy is one of the most effective techniques of rehabilitation treatment. This is apparently a very generic method because it allows any activity in which the patient is involved actively in 'doing' something itself to be stimulated.

The term 'occupational therapy' in Italy refers above all else to rehabilitation of the activities of daily living (ADL), whereas in the United States of America it has a much broader meaning.

The rehabilitative principle at the basis of occupational therapy is based upon the possibility of stimulating in cases of people with Alzheimer's disease the procedural memory. which is a type of implicit memory which in general is preserved until the advanced stages of this disease. The patient can thus remember sequences and procedures, of a complex kind as well, and can learn new ones, something that is not equally easy with types of learning that are based upon other mnestic functions.

OT therefore is concerned with the limitations to the functional capacities of a person with dementia. The primary objective of action with occupational therapy is thus to rehabilitate – or maintain active – a function in order to conserve autonomy for as long as possible in the activities of daily living.

People with dementia often are able to do many things but they have stopped doing them for reasons unconnected with their memory loss. For example, the patient can still be able to wash himself or herself or get dressed but the requirements of management often lead the carer to accelerate these actions and to take the place of the sick person, making him or her lose the capacity to carry out these activities.

Yet for the sick person it is important to remain active and busy in relation to things that are useful for him or her; to be able to successful carry out an activity and see a concrete result of what he or she has done makes the moment that has been experienced gratifying and has a positive impact on his or her self-esteem.

This is the result at which OT aims and this is certainly much broader than the rehabilitation of a function alone. We can thus see occupational therapy as a holistic rehabilitation method that aims at the physical and mental recovery of the patient and which through the exercise of directed activities (ones that facilitate the process of adaptation) and relevant activities (directed towards action, towards daily concerns, and to adaptation to the surrounding environment) seeks to maintain the patient at the highest possible level of autonomy and independence.

Occupational therapy is thus based on the thinking that directed activities, or occupations, including interpersonal and environmental components, can be used to prevent and mediate dysfunctions and obtain the greatest level of adaptation. Through the introduction of various activities and occupations where potentialities have been identified, OT seeks not only to reverse a functional deficit (or a particular lost ability) but also, and above all else, to retrieve it from a cognitive and functional point of view, as totally as possible for the patient and his or her environment – the family, his or her work and his or her relational life.

In order to engage in a correct action, it is indispensable to identify activities where the patient had, or still has, his or her ability on which to base a directed programme so as to strengthen them.

For this reason, there is a move from complex activities for patients with light and moderate levels of cognitive deficit to very simple activities for patients who are in a grave state as regards their illness.

Given its effects on autonomy and self-esteem, this kind of rehabilitation is thus one of the therapies that is one of the most useful with patients who suffer from Alzheimer's disease.

The rehabilitation approach of OT is not limited to the patient but is also addressed to the environment that surrounds him or her in order to make it more useable, projecting and creating environmental aids and prostheses *ad hoc*, where the cognitive and functional state of the patient and his or her behavioural disturbances are taken into account.

The patient through the methods of OT can also be enabled to assess his or her own creative capacities by using materials of various kinds (for example, cloth, cardboard, plastic, polystyrene, etc.) in order to transform them into finished products through the use of hand and decorative techniques (decoupage, bricolage, puzzles, etc.).

In proposing OT treatment, as is the case with all rehabilitation methods applied to geriatric people, one has to identify activities that are suitable for the person involved and also motivate him or her. Where there is a difficulty in carrying out the activity that has been proposed, the therapist must intervene (prosthetic action) in the most discreet way possible and allow the patient to complete the activity so that he or she has the feeling that he or she had done this on his or her own ('activity without defeat'). In the choice of the activities which have to be rehabilitated or kept whole with OT methods, there will be a primary choice of those pathways that have been chosen or most proceduralised during the course of development, such as for example self-care (hygiene, dressing, alimentation).

If the basic functions have still been conserved, other activities can be chosen which will be different with different people, always preferring those pathways that have been learnt (for example, skills, domestic activities). Lastly, the activities can be chosen from favourite hobbies, and an interview with the family relatives of the patient can provide the information to identify what these are.

Remotivation therapy

Remotivation therapy was born in the United States of America in the middle 1950s with Dorothy Hoskins Smith, a teacher of English literature who worked as a volunteer at the Philadelphia State Hospital. This therapy was initially used with psychiatric patients. It is a cognitive-behavioural method that is also used with patients with a light to MMSE (mini mental state examination) level of cognitive deficit or, whatever the case, still able to follow a conversation, and who have depressive symptoms that are not grave.

This method is employed chiefly with groups (made up of 10-12 people) and it is only rarely applied individually. During the meetings, which must be short, directive and strongly structured, subjects of current affairs are addressed or topics which concern the surrounding reality or which are near to the reality of the people involved. The principal objective of this therapy is to limit and counter the tendency to isolation of people with dementia or depression. During the course of these meetings the patient has to be stimulated to enter into a relationship with the others and, when remotivated, to interact with the environment that surrounds him or her so as thereby to retrieve past interests or develop new ones, creating connections between the objective world and his or her reality. Before beginning the therapy, it is of fundamental importance that the health-care worker can engage in an in-depth analysis of the past and present features of the patients, the character of the patients who are taking part in the meetings, their interest, their hobbies and their habits, so as to then form groups of people with similar cognitive capacities and similar interests.

Validation therapy

'Validation' therapy, which was proposed by Naomi Feil in 1967, is a method recommended for patients with cognitive deterioration of a moderate or grave level with associated behavioural disturbances. It can be individual therapy or group therapy.

Through listening the therapist seeks to know the patient's vision of reality (which can lead him or her to live periods antecedent to his actual experience) so as to create a meaningful emotional contact (emotional validation). The principal objective does not lie in bringing back the patient to current reality (which could increase his or her sense of anxiety or insecurity) but, in contrary fashion, it is to immerge him or her in his or her 'world' so as to understand his or her forms of behaviour, feelings and emotions.

Thus through verbalising his or her feelings and emotions which are 'validated' by the therapist and companions of the group, the patient can retrieve his or her self-esteem side by side with the perception of being accepted as an individual who is capable of suitable relationships, and as an effect jr or she can also improve maladjusted behaviour and interpersonal relationships. This therapy is utilised in order to attempt to reduce behavioural disturbances such as wandering, agitation, aggressiveness, anxiety and suspiciousness.

The group meetings (5-10 people) can last for 30-60 minutes and can be held once a week. In the group meetings each participant performs a specific role which has to be agreed upon at the beginning of the therapy. The meetings must envisage four separate moments, which are dedicated to conversation, to music, to movement exercises and to alimentation (with the distribution of drinks and biscuits). In these meetings reminiscence in a narrow sense is flanked by stimulations that can foster the interaction between the patient and the therapists. All the activities engaged in during the meetings are directed towards fostering dialogue with the patient which should be led to express outwardly his or her vision of reality. The therapist has to comfort this vision of the patient and enter into contact with it empathetically, demonstrating understanding and participation and adding elements that are consistent with that patient's vision of reality.

Music therapy

The most up-to-date definition of music therapy is the definition approved and agreed by the international community on the occasion of the eighth World Congress of Music Therapy of the World Federation of Music Therapy (1996): 'Music therapy is the use of music and/or its elements (sound, rhythm, melody and harmony) by a qualified music therapist, in an individual or group relationship, within a defined process in order to facilitate and promote communication, relationships, learning, mobilisation, expression, organisation and other therapeutic objectives worthy of note with a view to meeting physical, emotional, mental, social and cognitive needs. Music therapy has as its tasks that of developing the potential and/or rehabilitating the functions of an individual so that he or she can obtain a greater integration at an intrapersonal and interpersonal level and, consequently, a greater quality of life through prevention, rehabilitation or therapy'.

This therapy is utilised above all else for patients with light to moderate cognitive deficits who have associated problems of language or behavioural disturbances. Positive results have been reported in more severely impaired patients as well, both at a socio-relational level and at the level of behavioural disturbances. This therapy can involve group action or individual action, in the gravest cases. and can be implemented in two ways – one is receptive and the other is active.

Receptive music therapy is based upon listening to sound, rhythmic and musical messages and it fosters the recall of memories, facilitates associations and allows an increase in verbal and non-verbal communication.

Active music therapy is based upon the production (singing) and emission of sounds using musical instruments (small blocks of wood, coconut shells, maracas, little bells, triangles, bells, plates, bongo drums, tambourines), objects and parts of the body. *Singing*, which provides an awareness of being there at that moment, if it takes place in a group, creates or strengthens a sense of belonging to that group.

Music therapy has as its objective the development of a process of relating with non-verbal communication as well, the understanding of which is also conserved during the most advanced stages of Alzheimer's disease.

It can also be used to reduce aggressive disturbances which are unleashed during daily life activities or during ones that the patient does not like very much (for example hygiene). It can foster relaxation during the advanced stages of the disease as well and the recall to the memory of pleasant memories and sensations which help the patient to express thoughts and emotions and to reduce vocalisations and agitation. Music therapy stimulates the 'cognitive' functions when rudimentary instruments are used for the production of rhythms and /or sounds, or it can stimulate the remote memory through listening to musical pieces that are known to the patient, and it can also be effectively utilised to indicate certain moments of the day (for example lunch time) or to foster falling sleep.

Movements with music, if the patient involved is guided, can be directed towards the reacquisition of the corporeal schema and tactile stimulation or, if the patient moves freely, it can be an exercise directed towards improving mood and movement in general.

Physical exercise

Physical activity (sport, gymnastics), in addition to having a positive impact on the reduction of the risk of developing dementia, is also useful at every stage because in addition to allowing the maintenance of residual motorial abilities it can contribute to a reduction of behavioural disturbances and an improvement in cognitive disturbances. In addition, it has a positive impact on the appetite, improves sleeping-waking rhythms and facilitates socialisation. If movement activities are engaged in within a group, it also has a positive impact on mood.

Physical exercise and aerobics can directly influence the cognitive functions, bringing about biochemical and structural modifications at a cerebral level which are translated into an increase in the proliferation of cells. Experimental studies have highlighted an increase in the proliferation of cells in response to physical exercise. In a recent study it was observed that in rats (both young rats and elderly ones) that engage in physical activity where the control group did not engage in such activity, learning and neurogenesis were strengthened. In addition, it has been observed that physical activity is associated with an increase in neurotrophic factors that are important for the growth and survival of nerve cells.

Context therapy

Milieu therapy (or context therapy) belongs to the field of cognitive-behavioural methods and applies the principles and procedures of a learning model developed by Skinner which is defined as 'operating conditioning'. It is a set of rehabilitative measures, carried out both individually and in groups, which is used in many psychiatric illnesses and in autism. Although controlled clinical studies which attest to the efficacy of such an approach, have not be carried out, this therapy is advisable in people with Alzheimer's disease in the guidelines of the American Psychiatric Association (APA).

Context therapy seeks to improve not so much the physical environment as the social and affective atmosphere, thereby helping the patient to deal with daily life activities and to reduce behavioural disturbances and disturbances of social conduct. It involves modifying/modulating the environment in which the patient lives so as to make it compatible with his or her functional capacities. It also has the objective of modifying the therapeutic expectations of the people who are providing care and of the patients themselves.

Operating conditioning, on which milieu therapy is based, utilises the technique of positive or negative reinforcement respectively to encourage or to discourage certain forms of behaviour of the patient. Generalised and direct positive reinforcement is used to obtain and maintain suitable behaviour and negative reinforcement is employed to discourage or to inhibit the repetition of inappropriate attitudes or reactions.

Phototherapy and multisensorial stimulation (bright light and Snoezelen therapy)

Bright light therapy or phototherapy is utilised as an attempt to improve the fluctuations of the sleeping-waking rhythms and help with the sundowning syndrome (this is a syndrome which involves recurrent confusion and an increase in agitation in the late-afternoon or the early hours of the evening).

Snoezelen therapy or multisensorial stimulation was created in the 1960s in Holland within the context of research into 'learning difficulties'. From the outset, in the therapeutic field, it has had the name of Snoezelen therapy, a Dutch term derived from the fusion of the two terms in Dutch for 'explore' and 'relax'. This is a method for people with grave sensorial deficits and is usually employed individually in multisensorial environments.

Multi-sensorial environments were conceived as places in which it is possible to engage in destructured activities (exploration, the use of objects, conversation) and with the 'freedom to make a mistake', without pre-established objectives that have to be achieved and with the aim of achieving relaxation on the part of patients who feel themselves to be safe.

A multi-sensorial environment is usually a room with white walls or with pastel colours (in order to optimise the effects of the illumination), with windows that can be darkened and which has floors and furniture that are made up of tactile (soft) materials: luminous panels that are sensitive to pressure, mirror balls, and image or coloured light projectors, files and folders made up of optic fibres. Tubes with bubbles that vibrate and change colour when they are touched, systems for colours and scents, objects that can be used outside the room and which have a role inside as well (dishes, cutlery, balls, etc.) are also used.

Multi-sensorial stimulation is seen as a sort of prosthetic and stimulating environment at one and the same time which should have positive effects in interpersonal relationships and anxiety-depression disturbances and which should also improve the sensorial capacities of the patient.

'Sand' therapy

Sand therapy (ST) is based upon three important elements: sand, objects and a container. Sand is something that is extremely ductable and is able to stimulate the creativity and the mind. This therapy is a strictly individual activity and takes place in sessions that are usually held once a a week and last 4-60 minutes. In itself, the activity involved is simple: the patient and the therapist sit on either side of a basin of sand. Miniatures are placed near the patient and these can be of people or of equipment, or natural elements (rocks, wood, grass, etc.), buildings or animals or coloured sand.

The therapist leaves the patient completely alone to express himself or herself and does not give any directives: during the first stage his or her role is that of being a silent spectator. The patient chooses the objects and the sand to use and positions (creates) them, moves them, or simply draws in the sand with his or her finger. All forms of behaviour, even those involving anger, are accepted. Only at the end of the creation does the therapist take a photograph of the representation that has been created and, if this is possible, comments on it with the patient. The comment stage can continue beyond the time established for the therapy: the therapist can show the patient a photograh of what he or she has created in other contexts as well so that the therapist can thus go on commenting on it. The photograph is also used to have a record of the modifications in the behaviour of the patient.

The objective of ST is to diminish the state of agitation and behavioural disturbances of the patient and to give him or her the opportunity to enjoy a pleasant experience through which he or she can express needs, worries or memories that would otherwise not be conscious. Sand therapy stimulates attention and concentration in the patient, fosters 'speaking about oneself', both during the creation of the image in the sand, which is itself an instrument by which to communicate internal states, and during the comments on the work. In addition, this technique stimulates the recall of memories and helps motorial abilities in patients.

Horto therapy (HT) and therapeutic gardens

This technique can be seen as a multi-sensorial (smell, sight, touch) cognitive-behavioural rehabilitation treatment. This form of therapy, which was created in Asian countries, began to spread in the United States of America at the end of the last century and it is beginning to be learnt about in Italy as well. Horto therapy involves activities relating to gardening and the cultivation of plants and orchards.

Various activities are engaged in: the preparation of the soil, the organisation of space, sowing, following plants grow, observing flowering and lastly cutting and harvesting. Plants that flower are used to stimulate sight, plants that provide a scent are used to stimulate the sense of smell, and plants with hairy leaves are used to stimulate touch.

This is a therapy which is used with patients at various stages of the state of dementia. The patient is placed in contact with the earth and already from the observation of forms, colours, shadows, lights and the scents (aroma therapy) of flowers he or she receives stimulations of a perceptive kind that can reduce his or her behavioural disturbances. Taking care of a plant or a flower stimulates affectivity, improves self-esteem and a sense of control over one's environment. In re-establishing contact with the earth and the environment there is a fostering of a sense of spatial and temporal orientation, socialisation and motorial activity, with positive consequences for depressive disturbances and anxiety.

HT is an activity that needs to be organised because taking care of plants requires rather specific periods of time and definite forms. Usually, horto therapy is engaged in every day, at pre-established times where the individuals or groups are led to the areas allocated to it. HT, especially at the outset, is a 'directive' activity where the therapist gives tasks and explanations and adopts the role of a leader and controls the situation (for example he or she explains how to water, when sowing should take place, etc.). Despite the need for the presence of the therapist, the patient is free to engage in the activities himself or herself, applying the methods and the strategies that have been learnt. If the activity takes place at a group level, the expert patients (who take the place of the therapist) can be flanked by new patients in order to foster learning by imitation. If specific objectives have to be reached (for example the exercise of specific motorial activities), the therapist will organise activity in the light of these objectives (for example specific movements or pathways are made obligatory).

Pet therapy

This is a rehabilitation therapy of a behavioural kind. The presence of an animal improves the life of the individual from a psychological point of view, decreasing his or her loneliness and depression, acting as a social support, providing an impulse to taking care of oneself and becoming a source of relevant daily activity. Pet therapy was born in 1953 in America and was the invention of the psychiatrist Boris Levinson.

When working with an autistic child he realised that his dog was an opportunity for affective exchange and playing and made the session more pleasant.

A man-animal relationship of an affective and emotional character is able to provide benefits not only of an emotional and psychological character but also one of a physical kind, such as the lowering of blood pressure and the slowing down of the heart beat. Its use has been extended to other illnesses, including Alzheimer's disease.

Through this process of stimulation which is prevalently sensorial in character, the patient manages to find certain benefits as regards some behavioural disturbances.

Many studies have demonstrated that the company of a dog (always in the presence of its instructor) reduces aggressiveness and agitation and improves the relational behaviour of patients. Interaction with an animal also encourages verbal and non-verbal interaction between the person and the animal, thereby stimulating not only the memory of the patient (animals can bring back memories of the past) but also his or her temporal orientation (the meal times of the animal and when it has to be taken for a walk), and his or her sense organs which are stimulated by the smell of the animal, by its colour and by the tactile sensation of its fur.

By a legislative decree of 6 February 2003, so-termed 'pet therapy' was officially recognised within the national health service.

Doll therapy

This is a rehabilitation method used both to achieve a diminution of behavioural disturbances and for the maintenance of cognitive functions.

Doll therapies have special characteristics as regard the dolls used (weight, position of the arms and legs, size and somatic features) that stimulate the activity of taking care of something. The patient is thus stimulated to activate tactile relationships and *maternage* which foster the management and in some cases the diminution of behavioural disturbances such as agitation, aggressiveness, apathy and anomalous motorial behaviour, and allow the exercise of certain kinds of memory.

Gentle care (prosthetic approach)

Gentle care is a prosthetic approach to care for people with dementia which was worked out by the Canadian occupational therapist Moyra Jones in the 1990s. It arose with the aim of stimulating the retrieval of the functional activities of sick people and to provide prosthetic measures to compensate 'from outside' what has been irremediably lost.

This approach, also, is not intended to 'replace' impaired functions but, rather, its objective is to assure the performance of daily life activities with the greatest safety and reduce the stress that they can provoke in the patient, and those who care for him or her, to a minimum.

The prosthetic approach seeks to attain this objective both through acting on the physical space (adaptations to domestic environments) and on those who deal with these patients so that they can acquire specific professional capacities (verbal and non-verbal communication, appropriate approach to care, etc.).

ABC of behaviour change

The ABC method is based upon the assumption that a specific form of behaviour is generated as a response to a previous event, thereby creating a behavioural chain between the antecedent, behaviour and consequences (ABC). Starting from this assumption, it becomes important for those who take care of a patient to engage in a descriptive assessment of the behavioural disturbance with the aim of helping to determine the reason for its occurrence. A careful description of the event is the best method by which to try to understand the possible causes behind it.

The use of the ABC behavioural chain in the form of a diary becomes a useful instrument in the gathering of information through direct observation of the event. The diary that is used should have three columns in which respectively the antecedents, the behaviour and the consequences are described.

An antecedent is everything that takes place immediately before a behavioural disturbance is manifested. It establishes the bases for the appearance of the subsequent form of behaviour. In the 'ABC' diary, in the column marked 'antecedent', one has to repeat the time, the place, who was present, what the patient was doing, and other data on the environment (the temperature, lighting, etc.). The behaviour has to be managed before compiling the diary, trying to ensure that not too much time passes before compiling the ABC. Other possible factors that can intervene should also be considered, for example an assessment of the state of health of the patient (infections, new intensification of a chronic pathology, etc.), the specific personnel, nearness to other patients, the noise level, etc. Lastly, it is useful to consider distant antecedents as well such as therapeutic changes and the family. In the column marked 'behaviour' one should record as much information as possible on how the patient behaved. In the column marked 'consequences' should be reported what happened after the behaviour (information on the person and on who has intervened to deal with the situation).

Everything that really happens must be described in an accurate way; what has happened or the emotional reaction to it cannot be interpreted. Something along the lines of 'he spat on the ground three times': this is a clear and measurable description. It is important to write the ABC diary as quickly as possible because it is very easy to forget the details of what happened even after a short lapse of time. Often one has to compile the ABC diary a number of times before seeing possible relationships emerging between the antecedents and the consequences; at times, however, this can even require a week.

An ABC diary is also a document that helps the medical personnel to assess in a better way the behavioural disturbances of the patient and to identify whether there are recurrent reasons (antecedents) that help to provoke it. In acting on the antecedents which have been identified as perhaps being responsible for the behaviour in question one will try to avoid the appearance of the consequent behavioural disturbance.

Dementia care mapping (DCM)

DCM was developed by Tom Kitwood and Kathleen Bredin and derived from an extension of an approach to care centred around the person of Tom Kitwood

Dementia care mapping is an instrument for observation that was invented at Bradford University to examine the quality of care as perceived by a person with dementia. It is based upon the philosophy of care centred around the person with the objective of promoting holistic methods with the patient and helping healthcare workers to improve the quality of care that is provided.

This approach to care for patients with dementia envisages the existence of 'mappers' who are not directly involved in the provision of care so as to avoid possible distractions. The mappers should usually work in pairs and spend six hours observing the events in a specific care activity. Every five minutes the mappers note the activity in which the patient is involved, his or her behaviour, episodes of wellbeing or malaise, noting if they are short or prolonged, and documenting all the positive events and if there are forms of behaviour on the part of the personnel which are not suitable or disturb the patient. A mapper only intervenes in extreme cases, for example if a patient is in danger or in the case of abuse. The mappers then analyse the data and provide a feedback to the personnel in order to explain the reaction of the patient to the care that has been provided and to draw up strategies for the improvement of the care that is offered.

DCM is widely used in the United Kingdom and abroad as the most effective method by which to provide training, feedback and planning in relation to actions involving care.

The training and the supervision of the personnel are essential elements in actuating a suitable method of care for patients with dementia – in particular the use of a systematic approach to the planning and assessment of care can also be useful in assuring individualised action centred around the person and his or her needs rather than only managing the problems that are perceived.

Spiritual and religious activities

If these activities have played an important part in the life of the person who has dementia, they continue to be occasions which are useful in stimulating socialisation, in fostering communication with other people, and in recalling memories. They can be a way of maintaining self-esteem and a sense of social belonging and of addressing the stress of the pathology.

'Stereotyping' (saying the rosary) and repetition facilitate participation on the part of patients, and the temporal-spatial cadence with which moments of encounter are repeated (Holy Mass, religious festivities) that foster orientation.

Dance therapy (DT)

The theoretical principle of DT is that the movements of the body reflect internal states. Through the guided movements of the body in a therapeutic situation a process can begin by which to improve the cognitive, emotional, social and physical integration of the individual.

Group dances help people to move out of their isolation. Rhythmic movement reduces muscular rigidity, diminishes anxiety and increases energy. Spontaneous movement helps people to recognise and trust their own impulses. And creative movement encourages self-expression and opens up to ways of thinking and acting.

From a physical point of view it improves coordination and muscular tone. At an emotional level it helps people to be calmer, more confident and to enter into relationships and to socialise. From a mental point of view, DT improves cognitive capacities, motivation and the memory.

Art therapy

This is a multidisciplinary technique that unites art, the psychological sciences and the pedagogic sciences.

Art therapy is a form of action that is actuated through the free expression of the creativity of the patient. Its goal is to offer the person an opportunity to produce 'artistic' works that can be an expression of thoughts and emotions. It can be engaged in individually or in groups.

The artistic product takes the place of speech and thus becomes an important means of communication by which to express positive moods or past suffering, thereby acquiring a cathartic and liberating character.

Art therapy seeks, therefore, to work on that part of the patient that is still preserved by seeking to strengthen his or her creativity and thus to reconcile internal conflicts, to increase self-awareness, to develop social capacities, to control behaviour, to reduce anxiety, to help social orientation, to increase self-esteem and to support motorial activities.

The artistic product has the role of being a mediator of the relationship between the patient and the specialist, it gives protection and containment and, although it respects the mechanisms of defence, it activates the creative resources, the emotions to be worked through and the residual capacities of the individual.

The task of the art therapist is that of accompanying the patient in discovering 'being' artistic and supporting, through verbalisation, awareness of what has been expressed in artistic form.

Thus the aim of art therapy is not to be interested in the artistic product in itself but, rather, to draw near to the interior experience that such a product expresses.

To recall emotions connected with the past means to replace the patient in contact with parts of himself or herself, with an identity that the disease tends to diminish.

Artistic production can alleviate the symptoms of depression connected with the deterioration of forms of autonomy, anxiety and confusion that have been created by numerous cognitive deficits. It can involve parts of the self that are still functioning in an active and moving process – which is what the artistic process is – and grant to the patient dignity and confidence as regards the capacities that the disease is undermining.

Biodance

From the Greek *biòs* = life, and dance, and thus 'dance of life', this is a practice that was conceived of and experimented with in the 1960s by the Chilean psychologist, anthropologist and sociologist Rolando Toro Araneda (1924-2010).

The elements that are involved in this practice are music, movement and the expression of emotions. The combination of these three elements can lead, through the activation of the affective core of man, to a direct experience of the concept of '*vivencia*' (a Spanish word that expresses the sensation of being alive here and now) as proposed by the philosopher Wilhelm Dilthey.

In Alzheimer's disease this technique of stimulation which is prevalently sensorial in character, in addition to the benefits of music, is said to produce positive effects as regards aspects such as the 'feeling dissolve', for the management of the affective difficulties of the patient, and the' therapeutic touch', which teaches how the patient can be given back an emotional balance through the touching of hands.

Biodance can take place behind closed doors or in the open, if practised without shoes, with comfortable clothing and limiting to the utmost the use of accessories such as watches, jewels and make up. It involves a succession of exercises (or *vivencie*) suggested by the therapist and characterised by specific music. Every now and then the therapist provides the indications that are needed to enter into this *vivencia*.

These exercises can be individual, in pairs, in small groups or can involve the whole group. For the most part, they are associated with one or more types of music. However, some exercises exist where music is excluded so that the participants can express themselves through singing or by keeping silent.

Aromatherapy

This is a form of treatment which attends to the wellbing of the mind and the body with the aim of obtaining psycho-physical relief through 'physical' action.

The kind of care, which is practised through massages, micro-massages and self-massage, takes advantage of essence oils.

This is treatment involving a stimulation of the senses which if placed within a multi-modal programme can with integrated with other techniques of cognitive stimulation.

This seems to be a form of treatment which is useful in the control of some behavioural disturbances (agitation), fosters relaxation and sleep, and reduces depressive disturbances.

The essence oils that are most used are extract of lavender, sage, balm balsam and lemon grass.

These oils, in addition to being used for body massages can also be used in bath water or sprayed into the air.

Aptonomia

Aptonomia (from the Greek '*hapsis*', 'touch', and '*nomos'*, 'rule') can be defined as the science of affectivity expressed through contact.

It was invented about fifty years ago by the Dutch medical doctor Frans Veldman and was applied for a long time principally to the relationship between parents and their children during the neonatal period.

The full meaning of the term 'aptonomia', therefore, one can well define as an approach to a human being in his or her entirety which, in expressing interest, respect and consideration – in a word 'affectivity' – confirms the other as regards the value of his or her existence.

The aptonomic touch, in offering an affective confirmation of the sick person, allows him or her to acquire a 'basic security' which sets in motion a series of positive psycho-physical phenomena and can also modify his or her capacity to respond to illnesses.

Actions to Support the Family and Caregivers (Psycho-Educational Measures)

Family relatives have a central

role to play in the management of a patient with dementia. Indeed, they often represent the principal resource of informal care for the patient.

In the majority of cases the caregivers are women (wives, daughters) with their family roles already well defined. In a sudden way and without being able to choose they often have to perform a new role which will transform in a radical way their lives (limiting or ending their jobs, forgoing social roles or contacts). The responsibilities and the intensity of assistance, the presence or otherwise of behavioural disturbances and the level of emotional involvement, the plurality of roles that are performed and the need to find always new and more difficult equilibriums can all produce in caregivers feelings of inadequacy, the idea that they are in a situation with no way out, and a sensation of isolation and of 'early mourning'.

For these reasons, caregivers are especially at risk as regards the development of psychological disturbances (anxiety, depression, being nervous, asthenia, lack of appetite and insomnia) and somatic illnesses. This state of health also has a negative impact on the overall wellbeing of the patient (and increases the risks of institutionalisation).

As a consequence, it is frequently the case that in caregivers there is to be noted a consumption of psychotropic drugs which is significantly higher than is the case in the rest of the population.

They represent a weak piece in care and require the provision of forms of support and moments of rest that can foster a recovery of their psycho-physical energies.

Programmes of education and support for family relatives thus become actions that are necessary and effective in supporting them in their tasks of care giving and in reducing their state of psycho-physical stress. A reduction of stress has a positive impact in diminishing the risk of having to resort to the institutionalisation of the patient and also has a positive impact in the quality of assistance that is provided.

Indeed, programmes of home assistance, information courses and training, self-help groups, various forms of respite-care (from day centres to authentic admissions to suitable institutions) and (individual or group) psychological support, have been demonstrated to be effective.

Programmes of counselling and psycho-educational programmes for the family unit have also been shown to be useful in alleviating the stress of caregivers. The psycho-educational initiatives seek to support the caregivers at an emotional level, to provide general information about the illness and local resources at the level of help, to teach strategies regarding cognitive stimulation, and to provide indications on how to be able to manage behavioural disturbances.

They thus have as an objective providing constant support to caregivers, assessing compliance with the forms of treatment that have been proposed (these actions envisage home visits), and assuring rapid access to the specialists of the team where this is needed.

The first stage of intervention envisages the provision to the caregivers of tables designed to explore the impact of the patient's illness on their lives and to assess their needs and their psychological condition.

The meetings that then follow envisage the introduction and the welcoming of the participants, with the description of each one of the participants, their histories and the difficulties that they encounter in their daily lives. During the course of these meetings information is communicated about the illness and the resources at the level of care that are available, about the strategies and techniques for cognitive stimulation, about strategies for the control of behavioural disturbances, with an assessment of the utility of the recommendations that have been offered.

What is expected from the family relatives is that they will acquire greater information about the illness, about possible sources of help, about the techniques of cognitive stimulation and about the control of behavioural disturbances that can be used in daily life with a reduction in the sense of isolation and discomfort with a possible consequent reduction of the set of symptoms associated with anxiety and depression.

As regards the patients, a slowing down is expected of their progressive cognitive decline, a greater control of behavioural disturbances and less resort to hospitalisation and to inappropriate pharmacological treatment and a consequent prevention of a further worsening of cognitive decline with a resultant delay in institutionalisation.

Environmental Rehabilitation Treatment (Compensatory Prostheses)

Cognitive disturbances also cause difficulties in recognising and using domestic environments. This can provoke the appearance, or amplify the intensity, of mental or behavioural disturbances with negative consequences for residual functional abilities and for the quality of life of the patient and his or her family.

Any rehabilitation action that wants to offer adequate assistance to an individual with dementia cannot but take into account these difficulties and has to take into consideration impacting on the physical environment, adapting it to the resources of the patient.

The adaptation of domestic environments must take into account both the cognitive deficit of the patient and the presence of sensorial disturbances (sight, hearing or movement) that are correlated with the pathology or the age of the person involved.

Indeed, deficits as regards the perception of colours in the cold band, the depth of space, and the relationship between the background and the foreground are far from being infrequent. In addition, difficulties as regards vertical movements in looking are often present. These disturbances of perception reduce the person's capacity to explore the environment and moving objects. It is often the case that to these problems are added a difficulty in interpretating auditory stimuli. These disturbances are aggravated by cognitive deficits which in themselves provoke difficulties in interpreting abstract visual symbols and in identifying the meaning of the use of objects. Or in memorising environmental points of reference and internalising special maps, and difficulties in understanding his or her own position in the environment so as to be able to alter his or her physical stance. Lastly, the reduction in the patient's capacity for attention worsens the possibility of decoding more than one stimulus at the same time.

In addition, the deficits of the pathology are then worsened by the functional reductions specific to physiological ageing such as slowing down or instability in walking, presbyopia, less ability to adapt to the dark, a vulnerability to making mistakes, a loss of peripheral vision and presbyacusis.

Lastly, there should also be an assessment of the presence of other concomitant physical pathologies that can provoke pain or other sensorial deficits.

To compensate for the difficulties that can derive from the deficits that have been described, and to make domestic spaces suitable to be being used, one should actuate specific compensatory rehabilitation ('prosthesis') measures. These compensatory measures should be of such a character as to assure the greatest safety without reducing the freedom and the autonomy of the patient. They should foster the topographical and temporal orientation of the person involved, the maintenance of his or her personal and familial identity, and avoid the appearance of mental and behavioural disturbances.

In the following sub-section the principal measures and some of the strategies that are most suitable in allowing the patient to conserve the greatest freedom and autonomy, assuring that he or she has the highest level of safety, will be briefly examined.

In order to assure the *safety* of the patient, the condition of the windows, the balcony, the garden, the terraces, the floors, the stairs, electrical appliances, lights, various kinds of equipment and utensils, medical products, disinfectants and detergents, plants, windows and window pains, should be tested so as thereby to reduce to a minimum the risks of a flight, a fall, a wounding, accidental cuts and electric shocks, and the ingestion of toxic materials. It is also useful to cover spikes, sharp edges and walls with soft materials in order to reduce the risks arising from accidental clashes with them.

To foster the *spatial* orientation of the patient one can utilise visual facilitations (for example a drawing of the WC on the door of the bathroom) or assure suitable lighting or simplify access day and night to domestic spaces (for example placing the bed near to the bathroom if the individual concerned is still able to use it but gets lost making his or her way to it, and leaving a night light on so that it can be reached). To facilitate the *temporal* orientation of the patient one can place very visible calendars and clocks that are easy to understand in the various spaces of the home.

To conserve the patient's *various kinds of autonomy* for as long as possible, the domestic spaces must be adapted to his or her cognitive capacities and objects that are still recognised and used should be made very visible (the WC should be made evident by covering the bidet, utensils that are still used should always be put in the same place). The kitchen should have electric or gas rings if the patient is still able to use them (rather than being prevented from cooking) and reaching the bathroom should be facilitated (written signs or drawings) rather than the patient being accompanied there.

To foster the control of *behavioural disturbances*, one can create a privileged space for resting where the patient can go or where he or she can engage in every kind of manipulative kind (a chest in which to loom for things) or relax (a soft corner), eliminating all those objects that could be destroyed (vases, things on the furniture, plants) or lost (keys) and covering objects that are a source of illusory phenomena of hallucinations (the TV, windows, reflecting shiny surfaces).

Some areas of the home are especially at risk when it comes to accidents and specific precautions should be adopted

The *kitchen* can be a place of accidents when the patient is still able to cook. This activity should be fostered but the patient should be supervised and the gas security switch should be covered so that it cannot be identified when it is not used. Security equipment should be applied for any possible gas leaks. If this is safer, the gas oven should be replaced by an electric one. Small electric appliances should be made safe. Systems to mix hot and cold water should be installed so that the water when it comes out will be 36-37° in order to avoid burns. Make the dishes that the patient still uses very visible and they should always be put back in the same place. Knives and material with a cutting edge, detergents and other toxic material should be locked away. Systems for the closing of drawers, cupboards, refrigerators and freezers should be identified.

The *bathroom* is a place of falls connected with the presence of slippery surfaces and the difficulties that are encountered in engaging in movements of sitting down and standing up in spaces that are at times enclosed and without supports. In order to avoid the patient remaining shut up inside the bathroom, the systems of closure from the inside should be removed. Anti-slipping mats should be used on the bottom of the bath tub or the shower. To reduce the risk of falls support bars should be placed near to the WC, the bath tub or the shower. Aids should be applied that allow the patient to sit when he or she is washing himself or herself (stools with holes through which the water can ruin, small chairs or tables in wood and/o plastic to be applied to the bath tub). The bidet should be covered when there are phenomena involving confusion between the bidet and the WC or the bidet should be differentiated from the WC by using different colours for each. The WC should be provided with supports so that the support level can be raised. Detergents and other toxic materials, including medical products, should be kept in a safe place. The sockets, plugs and cables of small electrodomestic appliances should be covered (for example the hair drier). The bathroom should be lit for the whole of the night so that its use can be facilitated. The mirror should be covered with a drape so that the patient does not recognise his or her reflection and exchanges it for an intruder or a thief. Objects that are commonly used by the patient (toothbrush, toothpaste, comb) should be always left in the same place and be visible but they should be removed when the patient is no longer to recognise their function or use them in an appropriate way.

As regards the *bedroom*, getting out of and into bed should be facilitated in order to reduce the risks of a fall; only objects and clothes that are used should be allowed to remain, carpets and bedside mats should be removed, the path from the bed to the bathroom should be facilitated by removing obstacles or using a ‘commode’ in the bedroom. Some spaces and drawers should be arranged so that with the material that they contain the patient can have free access in order to go through it, add things or tidy up if he or she demonstrates such behaviour. These should br materials that he or she can handle without there being any danger (jerseys or old clothes).

In the *corridor* ornamental and obstructing objects should be removed, as well as telephone cords. Electric cables or other obstacles on the habitual pathway of the patient (above all if he or she engages in wandering) should also be removed because they could trip him or her up. Do not use wax on the floors or only anti-sliding wax should be used. One should also assess whether the lighting is suitable and homogenous. The presence of mirrors and paintings if they are a source of agitation for the sick person should be reduced (or eliminated).

Stairs are frequently the cause of falls when difficulties in walking begin to manifest themselves. If the house has a number of floors, it is advisable to place the living space of the patient on one floor. If stairs have to be used, they should have a bilateral banister for the whole of their length and the edge of each step should be highlighted with anti-slipping material. There should be an assessment of whether the lighting is suitable. All objects that are a potential source of tripping should be removed and a small door should be installed to make sure that access to the stairs is safe.

As regards *windows*, transom windows should be user or grills should be installed to avoid them being used by the patient as inappropriate exits. The normal handles should be replaced with extractable handgrips. All furniture that could be elements that help the windows to be used (chairs, tables, armchairs) should be kept at a good distance.

Doors can also become a problem when they give access to external areas (the ‘flight’ risk) or ‘dangerous’ areas (access to storerooms, laboratories containing equipment). In contrary fashion, it is important that some doors are easily identifiable by the sick person so as to allow a comfortable use (the bathroom door, the bedroom door) of the domestic spaces. One could, for example, colour doors and handles with the same colour of the wall so as to make the door less recognisable, apply latches to a position that cannot be reached (high up where the patient will tend not to look) and avoid placing hangers near to doors because they foster them being recognised by the patient.

If, instead, one wants to facilitate the recognition by the patient of the door, it should be painted with a colour that is different from its handle and the wall. However, the key should be removed to avoid the patient locking himself or herself in the room even accidentally. It can also be useful to put things on the door that foster the recognition of the environment to which the patient has access (a drawing of a WC, the drawing of a bed) so that he or she is able to recognise it.

Lastly, it can be difficult to recognise *windows and window panes* if their surface is transparent or reflects, with the consequent risk of being hit, bruises, cuts or the appearance of agitation and/ or hallucinatory phenomena provoked by seeing things or people outside the windows which cannot be reached because of an erroneous interpretation of spaces. Window tapes could be applied, the window panes should be made opaque, or they could be replaced with another material which is not transparent and does not reflect images.

As regards colours, it is important to prefer bright ones, with delicate shadings that are not easily perceived, and to create a clear distinction between horizontal levels and vertical ones. The colour of the horizontal levels (floors) must give a sense of solidity, the impression of standing in security. In polyvalent areas of the home, it is useful to employ colour tones that are relaxing. ■

3.3 Good Palliative Care is a Basic Human Right

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The Declaration of Human Rights sets out that all human beings are born free and equal in dignity and rights. The declaration clearly states that no one shall be subjected to torture or to cruel, inhuman or degrading treatment; therefore it is clear that, to fulfil our duty of care, we must use the skills we have to provide good care and relief of suffering to those who are dying. However, it is important to remember that, as Dame Cicely Saunders said, we should 'help you die peacefully but also live until you die'. It is that focus on living, rather than seeing death as a convenience or an end point in itself, that is the focus of this address.

Palliative care for patients with neurological disease almost always starts at the time of diagnosis. Those with neurological disease know that there is no specific treatment to reverse the progress of the disease, although interventions with physiotherapy, and sometimes with drugs, will slow disease progress. The diagnosis is devastating and patients have to adapt to their physical symptoms as well as cope with the emotional turmoil that their diagnosis imposes. The social changes are seismic. Many patients, whether they have a religious faith, are agnostic, or are of no faith, will have questions and turmoil around their existence that would fall into the classification of the spiritual domain. A terminal illness has been defined as 'an inevitably progressive condition that cannot be reversed by treatment and that, as a consequence of the illness, the patient is expected to die within six months'. However, it is very important to recognise that the trajectories of the course of a disease vary widely.[1]

All too often the uncertainty for the person who is dying is a difficult concept for them and those providing care to accept. The course of disease is surrounded by uncertainty. Sometimes patients appear to suddenly deteriorate, only later to improve dramatically, leaving everyone surprised that they are still alive.

During the course of illness there will be times when the patient becomes unstable with an unexpected urgent problem which, if not attended to, would result in the patient's deterioration and death. An example of this is a gastric haemorrhage as a secondary side-effect from non steroidal drugs. At other times the patient may deteriorate, in an expected pattern. They need urgent support and yet this is not a full blown emergency. An example of that situation is a patient with remitting and relapsing multiple sclerosis, where the deterioration may be quite sudden but they may improve again although never regaining the function that they had before that episode. If these episodes are not appropriately dealt with, the patient's quality of life will be devastating damaged and recovery will be all the harder.

The role of palliative care is to help patients reset their hopes and aspirations to be more realistic. For example, bringing family events or celebrations forwards, ensuring that birthdays and other key dates are met and in the process abandoning very long terms plans. In order to reset hopes and aspirations the reality for the patient must be improved, which requires the best of clinical skills.[2]

Accurate diagnosis is needed to holistically address all the causes of distress for patients within the physical, the social, emotional and spiritual domains. Without addressing all domains in a holistic way, the major components of distress will be missed and their interplay on physical manifestations of a disease will not be understood.

It is often thought that we can diagnose dying accurately, yet even when the prognosis is very short there needs to be an explicit recognition of the uncertainty around diagnosing dying and the need to work with and within this concept.[3] This review demonstrated clearly that clinical decision making needs to allow for recovery where that potential exists, but also needs to recognise that futile interventions should be avoided.

Patient care is incomplete without good communication. In Cardiff we developed a six point tool kit for use in all types of discussions where difficult conversations were had. Firstly it is important that the patient is comfortable. A person who feels sick or who is in pain or is sitting uncomfortably cannot have an in-depth conversation of meaning. Secondly, the importance of non-verbal communication needs recognition: the non-verbal and cues from the clinician portray an enormous amount of information as does the non-verbal language from the patient and those with them. A third key skill relates to listening actively; few clinicians are good at listening and the vast majority unfortunately talk at the patient rather than make sure that they listen for about 80% or more of the time during their conversation. Fourthly, questioning using open questions is very important as the more open the question, the more information is gathered. Another very useful tool in communicating is reflection, when a difficult word or phrase is reflected back to the patient for the patient to build on it with further explanation and exploration. The sixth, possibly the most useful of all, is summarising. A quick summary will mark to the patient what they have been saying has been heard and recognised, that their problems have been acknowledged and will allow an agreed plan to be developed.

In Wales we have been collecting information on patients thought to be in the last 48 hours of life. After review of over 26,600 patients, it has been found that the vast majority of these patients die within the anticipated time frame, with an average time of 2.4 days from that the time that they were thought to be irreversibly dying of their disease. However, this data also has emphasised the need for review, with a range of less than 1 day, up to 88 days from the time that the patient was deemed to be irreversibly dying. This data emphasises the need for constant review and thinking about what is happening to the patient.

Much has been written in international literature about dignity. In 1992, Dame Cicely Saunders defined dignity as 'having a sense of personal worth'. Harvey Chochinov's work has demonstrated that care that "confers honour, recognises the deservedness of respect and esteem of every individual – despite their dependency, infirmity and fragility – could lie at the heart of care that conserves dignity".[4] When issues of assisted suicide and euthanasia are discussed, dignity is often cited as the main reason to facilitate these actions in patients. However, Chochinov's work has shown clearly that the person's sense of dignity can be enhanced by being cared for well and conversely can be destroyed by inappropriate and insensitive care. Within every consultation it is important to explore what a patient wants and needs, where possible hopes and aspirations may lie and support building on these in a realistic way.

Quality of life is linked to quantity of life. An interesting study on patients with metastatic non small cell lung cancer has shown that early palliative care intervention significantly improved their quality of life, their mood, with lower depression scores, and their survival times prolonged from a mean of 8.9 months in the control group to 11.6 months in the intervention group ($P = 0.02$).[5]

One reason that these patients may have been living longer is that they probably avoided futile interventions, such as chemotherapy that would have been debilitating, as well as being well supported with their physical and emotional concerns so that they were not dying earlier from exhaustion.

Withdrawing or withholding treatments that are not achieving their therapeutic goal is not euthanasia by the back door. It is unethical to treat a patient if the therapeutic goal of that treatment cannot be reached. Everyone will die at sometime and recognising a natural anticipated and accepted death is fundamentally different from deliberately foreshortening life. When an interventional treatment is stopped the patient may die quite quickly, as in ventilation cessation, or may live much longer than anticipated because they were in fact being harmed more by the treatment than they were benefitting from it. However, most of the time patients seem to die when they feel comfortable to let go of life and when their disease has progressed to such a point that they accept dying. This is fundamentally different to the patient who seeks assisted suicide or euthanasia, where the express intention is to bring about their death as rapidly as possible irrespective of how long their life expectancy would otherwise be, whether it would have been days, months or even years.

It is therefore worth thinking about why patients request euthanasia and how a clinician should respond. It seems that the majority of requests are related to fear of pain, fear of loss of dignity and fear of losing control and losing autonomy, as well as fear of being a burden. In other words, fear of future is stronger than distress of the situation of the present as when it is a motivator to seek assisted suicide/euthanasia.

The issue of autonomy is one that is often brought forward by campaigners for physicians assisted suicide/euthanasia (PAS/EU), as if it is an absolute. However, autonomy does not mean "I want therefore I get". Autonomy is relational; in other words a person's living and dying have an effect on those around them, although a spouse or other adult members of the family are often involved in discussions around care, children and teenagers are usually forgotten about. Yet the impact on them of the death of a parent or grandparent can be the most devastating life event that they will ever have. Children who are not supported prior to or during bereavement have worse social outcomes, worse academic attainment, higher incidence of depression and drug abuse, higher incidence of teenage pregnancy and are more likely to get a criminal record than those children who have not suffered in this way. A study that we did in Wales showed that there are thousands of children who have lost a parent or sibling or a very close and significant friend. Yet the vast majority of these children have no support whatsoever and are often excluded from information when a death is anticipated.

So let me now turn to the issues of PAS/EU and the pressures around the world to legislate for these to be options in care delivery. Assisting suicide and dying well are not synonymous. Managing a dying patient during their last illness requires frequent input, constantly revising the care that is planned and supporting them along the road towards their natural and anticipated death. The analogy is a little bit like driving a car down a twisted country lane where you constantly have to be adjusting the speed and the steering in order to stay on course well. If one uses this analogy in relation to PAS/EU, it is a little bit like adjusting the steering wheel and putting a foot on the accelerator; of course the car will be rapidly destroyed as it comes off the road and hits a tree or goes over the side of a cliff.

It is important to be clear what one is talking about. Physician assisted suicide (PAS) is where a patient is prescribed a lethal drug by a doctor and the patient then ingests it themselves. The prescription is issued with the intention of assisting the patient's suicide. In physician administered euthanasia (EU) the doctor injects a lethal cocktail of drugs deliberately to bring about the patient's death as rapidly as possible. It is worth noting that the cocktail of drugs used is not dissimilar to that used in execution of criminals by lethal injection in some countries such as the USA.

A desire for death is known to be linked to feeling a burden, particularly when patients have psychological problems.[6] Depression and hopelessness in patients are known to be mutually reinforcing independent predictors of a desire for death[7], and major depression is significantly linked with the desire for euthanasia or physician assisted suicide in palliative care patients with cancer. [8]

The influence of the physician in a consultation should not be underestimated. The patient who says that they want to die and for whom that request is processed, however sensitively it is done, is given the subliminal message that actually you, the physician, agree that they would be better off dead. Without being explicit, it confirms their worst fears, and can also imply that the future is so terrible that nobody has spoken about it and their death is the only option.

However, if the physician responds gently and by exploring the patient's concerns, seeking clues as to what, however small, can be done to make today better and where their fears lie, with a view to allaying those fears, the patient gets the subliminal message that they are worth you, the physician, working hard to improve things for them.

Any legislation that is proposed has to be surrounded by watertight safeguards, but the evidence from around the world is that such safeguards do not exist. So let's look at sound decision making, such as the decision to end one's life. For such a decision we need to have accurate information, the capacity to make that decision, and to make the decision in a voluntary way free of coercion.

Considering accurate information, it is known that diagnostic errors are widespread; Significant error such as the misdiagnosis of terminal illness occurs in 5% of cases and 30% are found at post mortem to have died from a different condition to the one recorded on their death certificate.[9] Predicting the prognosis is notoriously inaccurate and medicine is at best a probabilistic art. I myself have had patients who have been alive years after they were expected to die within weeks or months and, as already highlighted above, even when patients are thought to be in the last 48 hours of life about 3% of them improve unexpectedly.

Assessing mental capacity to make the decision is not simple. Mental capacity, written down in law looks simple and sounds like something objective, but its assessment is to ensure that patients are protected from harm, either harm to themselves as in a suicide prevention strategy or harm from others or harm that they may do to others.[10] In advanced neurological disease it has been estimated that around half the patients have significant cognitive impairment that goes unrecognised. Depression, as an impairment of capacity was found to be present in around 1 in 6 patients in Oregon who had passed all their tests for physician assisted suicide.[11] Indeed, the study concluded that the current practice of the Death with Dignity Act (in Oregon) may not adequately protect all mentally ill patients.

Coercive forces can also influence a patient's decision. Such pressures may be internal, as in feeling a burden, or external, such as the financial cost of care. In addition, it is worth remembering that many patients have a fluctuating desire for death so that a patient who is in despair at their situation and wishing for death may, weeks or months later, have found a renewed zeal for living. Unfortunately, coercive pressures can come from within a family, particularly where financial matters are involved and some family members stand to inherit a significant amount of money if the person does not live for very long. Another subtle and coercive influence that is often forgotten about in such discussions is the influence of the doctor themselves. The doctor who him or herself feels pessimistic about their role in medicine, the future and may be burnt out as a clinician, will give a sense of hopelessness to patients. Pressures on doctors such as saving bed costs or clearing hospital beds, as well as the problem of mental and physical exhaustion, can make the doctor more liable to give a subliminal message that death is a solution to a problem. In addition, societal pressures can have a bearing, whereby the person sees physician assisted suicide and euthanasia normalised around them and that normalised activity then becomes a societal expectation.

Many of those with severe disability, and that is not a homogenous group, find that care currently discriminates against them. They often have to fight to be treated adequately and as effectively as a person who does not have a chronic disability. They can feel under pressure that they ought to die even though they still want to live, but may have neither the energy nor the ability to express such thoughts clearly, thus becoming victims of coercive pressures around them.

In the UK the Director of Public Prosecutions guidance on prosecuting in the case of an assisted suicide has emphasised the power differential between a doctor or nurse and a patient, and stated that a prosecution is more likely if a doctor, nurse, other healthcare professional, or professional carer, whether paid or not, or any person in authority, such as a prison officer, acted in a way that assisted a person's suicide. His prosecution guidelines also recognised that sometimes relatives will act out of despair and compassion, but that taking them through the courts and into the punitive system will serve no benefit to anyone; hence his guidelines have recommended against prosecution if the person had a voluntary, clear, settled and informed wish and decision to die and the suspect who has assisted them was wholly motivated by compassion.

It is worth looking at what has happened in other jurisdictions around the world. The reasons given in Oregon by patients for assisted suicide include a sense of lack of autonomy, feeling unable to enjoy or join in activities of daily living, loss of bodily function, loss of dignity, fear of being a burden, intractable pain or fear of pain and for a small number, the fear of the cost of healthcare. In Oregon the number of lethal prescriptions issued has risen 4 ½ fold since the Oregon Death with Dignity Act came into force in 1998 and just over half of those prescriptions for lethal drugs are actually used to commit suicide. It is not known what is happening to the remaining drugs that have been prescribed and dispensed but not ingested. It seems that in Oregon a small number of doctors are writing more and more prescriptions since the number of prescriptions has risen far more rapidly than the number of doctors who are writing the prescriptions. Although the Oregon Death with Dignity Act requires patients to be referred for psychiatric opinion if psychiatric disorder is suspected, year on year the numbers of referrals have dropped to almost zero and in some years have been zero.[12]

It had been suggested that Oregon is an example of where the legislation has been enacted well, but there is no central prescription register, no collection of unused drugs and no way of monitoring non-compliance with their law. A study by Battin *et al.* suggested that the vulnerable were not at greater risk than others in the population.[13] However, the Oregon situation cannot be extrapolated to the rest of Europe for a variety of reasons. Firstly, to access hospice care in Oregon the patients must sign out of active treatment. There is no specialty training in Oregon, nor the Netherlands and in Belgium specialist training is relatively short compared to the UK. The most significant criticism of the study is that the age group in which the maximum of PAS deaths occurred was the 65 – 75 age group yet this group was specifically excluded from the analysis. Looking at the Oregon numbers, on a population basis alone, this would suggest a similar system in the UK would result in about 1,100 PAS deaths per annum across England and Wales.

The Belgian legislation required that a patient has ‘unbearable physical or psychological suffering which cannot be alleviated and is caused by life threatening and incurable, accidental or pathological illnesses, for a patient to be eligible for euthanasia. Although 1 in 50 of EU deaths in Belgium occur and are recorded, it is estimated that an additional 50% occur outside the law and there is clear evidence through the media and case reports that their law has been extended widely. For example, Nathan Verheist suffered from a botched sex change operation and this was viewed as grounds for euthanasia. Their law has been extended to children despite objection by Belgian paediatricians and ongoing campaigns in Belgium.

But the last word in all this has to go to doctors. A recent survey by the Royal College of General Practitioners showed that 77% of GPs do not want the law changed in the UK and to date, the British Medical Association and the Royal College of Physicians, following a consultation in 2008, also opposed the change in the law despite a major publicity campaign in the UK by the organisation that is pushing for legalised PAS in Britain.[14]

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THIRD SESSION

MODELS OF A NETWORK OF INTEGRATED ASSISTANCE

1. An Integrated Model of Care: the Case of Veneto

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The SSN was founded upon the principles of universality and accessibility. Since the end of the century the maintenance of high standards of care and treatment, conjoined with these principles, has been in a state of crisis, above all else because of changed national and regional socio-economic conditions, the increased needs of the populations as regards health, and demographic changes.

Since the first years of the twenty-first century, in Veneto the problem has been raised of how to conjoin, in the neurological field as well, universality and accessibility with respect to diagnosis and treatment with economic and managerial sustainability.

The observations of professionals over recent years have been taken on board by the regional authorities and translated into the new PSSR 2012/2016 and other planning documents.

The region of Veneto has about 4,900,000 inhabitants, of whom 51% are females, with an average age of forty-four for women and forty-one for men; its birth rate is 10 for every 1,000 inhabitants. The geographical distribution of the population is very heterogeneous inasmuch as a half of the communes have less than 5,000 inhabitants, only a fifth have more than 10,000, and five Provinces have between 800,000 and 900,000 inhabitants and two have about 200,000.

In the year 2009 individuals of the age of sixty-five or over numbered 960,000 and people over the age of seventy-five made up 9.4% of individuals resident in the region.

There thus emerged a model of an integrated network in Veneto – which is now at various levels of completion – for certain neurological diseases, and not only degenerative ones.

The neurological diseases of elderly people that have the greatest epidemiological and social/health-care impact are: 1. *cerebrovascular diseases* (the first cause in absolute terms of disability, the second cause of dementia after Alzheimer's disease, and the third cause of death after neoplasm and Alzheimer's disease) with more than 9,000 new cases of ictus every year and with costs that are greater than 15,000 euros for each patient. 2. *Parkinson's disease and forms of Parkinson's disease*: there are over 18,000 cases of these in the region of Veneto; and 3. *Alzheimer's dementia and other dementias*: there are about 50,000 cases of these at the present time in Veneto.

The Stroke Network

The stroke network functions and is distributed throughout the territory of the region of Veneto. The application of thrombolysis has been steadily increasing (over 9% of ischemic ictus cases are subjected to thrombolysis), with high levels in certain centres (in Verona over 40% cases of ischemic ictus receive thrombolysis).

This model has been appreciated by the Canadian Joint Commission (Treviso has already been accredited) and will be implemented in one of the Provinces of Canada (Ontario, Manitoba).

The principle courses of action that have been chosen are the identification of Hub and Spoke centres, the sharing of protocols for the management of transfers and back-transport, the activation of channels of constant communication, rapidity in connections between centres, and the promotion and the development of systematic and continuative activities of auditing within centres and between them

The Classification of the Centres

Second-level ictus units: *these are structures of a semi-intensive kind* that are located in hospitals and they provide neurology (active surveillance and the systematic use of thrombolysis day and night), neuro-radiology (with the possibility of endovascular treatment), and brain surgery.

First-level ictus units: *these are special structures* that are located in hospitals and they provide neurology (active surveillance for twelve hours and availability), the systematic use of thrombolysis, and the possibility of surveillance of patients.

Structures for ictus that are located in other hospitals than where the first and second level ictus units are located and which belong to institutions that provide neurology, internal medicine and geriatrics. These do not have the ability to provide thrombolysis.

The number of hospital beds involved is 110 (1 bed for every 44,000 inhabitants and 1 bed for every 100 stroke patients). The stroke network in the year 2012 with a Hub and Spoke coverage provided for 12.6 cases of treatment with thrombolysis every 100,000 inhabitants and 3.4 uses of thrombolysis every 100 square kilometres.

The Parkinson's Disease Network

Parkinson's disease (PS) is the second most common neurodegenerative disease after Alzheimer's disease and it has a prevalence estimated at 2% in the seventh decade of life; it is the most typical and frequent form of Parkinson-style disease (80%) whereas the remaining 20% of Parkinson-style diseases can be atypical, secondary (for example vascular) and genetic.

In Veneto it is calculated that about 18,000 patients have Parkinson's disease or Parkinson-style diseases.

Parkinson's disease has dedicated to it a network of neurological diagnosis, treatment and care that is present and distributed throughout out the region of Veneto, even though this network is not a formalised one. The clinics and the people who have by now worked in them for many years had already created an informal network, sharing training initiatives and/or research programmes.

Some health-care companies offer clinics that are characterised by greater continuity as regards care and treatment and teams which have at least two neurologists, the provision of medical products in all areas through the creation of therapy programmes where this is necessary, and the widespread use of therapies for patients at an advanced stage of their illnesses (DBS, apomorphine, duodopa). This is something that highlights the existence of an organised response to the most complex stages of this disease.

The critical points of this organised system are to be found in a certain heterogeneousness as regards the specialist services that are provided. There are problems with respect to the supply of care and treatment for patients who are at an advanced stage of the disease because of the frequent presence of multiple illnesses and complications and the need for a multidisciplinary and multi-specialist approach. Indicators of the process of the quality of the care and treatment that are provided are also not sufficient.

Once a light/moderate (the first and second stages of the Hoyen and Yahr – HY– disability scale) or an advanced stage of movement and non-movement complications (the third, fourth and fifth stages of the HY scale) have been defined, from the point of view of care and treatment it is advisable to make distinctions between the various activities that involve diagnosis and treatment which are based upon their complexity. The first stages can be managed directly by medical doctors engaged in general medicine, that is to say general practitioners, whereas the more complex stages require specialist skills and expertise (that is to say neurologists, geriatricians, physiatrists and physiotherapists).

An important aspect of the integration of this network is the identification of three levels of action as regards the diagnosis and treatment of Parkinson's disease, and these are based upon homogenous criteria.

The first level

This is the task of general practitioners, who during the initial stage of the disease formulate a diagnostic hypothesis and then during the subsequent stages of the disease carry out a clinical/pharmacological monitoring of the disease together with a neurologist.

The second level

This is the level where the diagnosis is confirmed and the neurologist formulates a therapy. The neurologist involved in the case works in a special clinic (in a local area or a hospital), examples of which are to be found throughout the area of the region of Veneto (see appendix 'A'). At this level there also takes place an integration with the other specialists in order to achieve a multidisciplinary management of the disease (something which involves treatment for complications covered by internal medicine and other accompanying illnesses, as well as physiatrists and/or physiotherapists for the management of rehabilitation).

The third level

This is the level where services relating to diagnosis and therapy are managed and which have a high level of complexity and technology (Parkinson centres; see appendix 'B') and which are for specific aspects of advanced diagnosis and differential diagnosis for other Parkinson-style diseases and for complex therapies (infusion therapies with duodopa and apomorphine and functional brain surgery), but which are limited (through rigorous screening criteria) to patients who are at an advanced stage of their illnesses.

Appendix 'A': Clinics that Deal with this Area

There is at least one in each hospital company (ULSS, district) and these assure the provision of the medical products that are required by the therapeutic plan for the patient.

Characteristics

– They engage in permanent clinical activity throughout the territory of the region of Veneto and this is done in suitable institutions.

– They must have the opportunity of having facilitated access to the third level as well as access to activities that are provided in the form of day services for special needs at the level of diagnosis and treatment.

– They must have access to diagnostic examinations involving neuroimaging, neuropsychology, and neurophysiology (on the basis of what is envisaged by the PDTA).

– They must be so organised that they have easy systems of communication with general practitioners and with centres specialised in caring for patients with Parkinson's disease.

– They must work together with centres specialised in dealing with patients with Parkinson's disease in relation to activities involving the training of general practitioners; specialists in the local area, nurses; other health-care workers involved in this field; and schools for Parkinson's disease for patients and their family relatives.

Appendix 'B': Centres for Parkinson's Disease

Centres for Parkinson's disease are present in the two AOU (Verona and Padua) and some hospital companies (Vicenza, Belluno, Treviso); those present in the AOU are in addition biomedical research centres in the field of Parkinson's disease and Parkinson-style diseases.

Characteristics

– Access to units of neurological treatment to which patients can be admitted for the provision of innovative therapies or therapies of great complexity which require hospitalisation (brain surgery, infusion therapies, and clinical experimentations of the first and second stages).

– Access to advanced diagnostic methods (neuropsychology laboratories, morphological and functional neuroimaging, genetics, pharmacology, neurophysiology laboratories, nuclear medicine).

– Preclinical or clinical research activity into Parkinson's disease of an international level.

– Information/training activity for the family relatives of patients.

Networks for Dementia

It is calculated that in the world there are about 24.3 million people with dementia and that there are 4.6 million new cases of this affliction every year.

In a more 'striking' way, one could say that in the world one person falls ill with dementia every seven seconds and that the current epidemiological trend means that the number of people with this disease will double every twenty years and that in the year 2014 there will be about eighty-one million people with this disease.

Alzheimer's disease (AD) is the most common form of dementia in both sexes and is responsible for about 60% of new cases of dementia every year, being followed by vascular dementia which is responsible for about 27% of new cases every year.

In Italy, according to the European Collaboration on Dementia, there are about one million people with dementia of whom about 60% have Alzheimer's disease.

According to the ILSA2 study, the incidence of cases is 12.5 for every thousand people every year. In the region of Veneto the prevalence of cases of dementia is about 65,000, of which more than 50,000 are cases of AD3. Survival after the appearance of dementia lasts on average about 7.1 years in cases of Alzheimer's disease and 3.9 years in cases of vascular dementia.

The Veneto Project for Dementias has its natural context in three fundamental elements: the Regional Social/Health-Care Plan of 2012-2016; local-area care through primary care; and guidelines for the reorganisation of health-care and social/health-care services for individuals affected by cognitive decline.

The network of care in Veneto is organised in the following way: the Regional Reference Centre for Cerebral Ageing (CRIC); the Centres for Cognitive Decline (CDC) in the hospital companies; the Multidimensional Assessment Units (UVMD) in the districts; high protection institutions for patients with Alzheimer's disease (SAPA) which are fifteen in number and are spread throughout the region – these have a total of 145 beds; residential institutions for patients who are not self-sufficient; Alzheimer's disease protection units; intermediate care and treatment (country hospitals); medical doctors providing primary care and treatment; home care and treatment; and integrated home care and treatment (ADI).

The overall system is explained in the 'guidelines for the reorganisation of social/health-care and health-care services for people with cognitive decline. DGRV 3542/07'. The PSSR identifies the following policies: the adoption of homogenous systems for data gathering: the creation of a regional register; the definition of PDTA; and experimentation with local-area forms of care and treatment that are able to assure a continuity in such care and treatment.

However, certain critical points can be found in the application of the above-mentioned DGRV 3542/071 and they are: a shortage of documents that explain the shared pathways of diagnosis, therapy and care to be found in the various ULSS hospital companies, on the one hand, and a lack of integration between the various points of the clinical/care network, in particular as regards the system of primary care and the social/health-care districts, on the other.

Following the recommendations of the regional government, the AOUI and the ULSS company of Verona have set in motion an Alzheimer's disease project whose goals are as follows: an improvement in the diagnostic capacities of general practitioners; the definition of shared diagnostic pathways of the first and second levels in the CDC; the development of specific PTDA for the various stages of dementia; the development of a shared system of information: and the creation of ongoing training.

And What about the Other Neurodegenerative Diseases?

Other neurological diseases (multiple sclerosis, amyotrophic lateral sclerosis and peripheral neuropathy) are the subject of assessment with a view to achieving an efficient organisation of pathways of diagnosis and treatment.

As regards multiple sclerosis, a PDTA on the Hub and Spoke model has been adopted in the Province of Verona and signed by the AOUI and the ULSS companies.

As regards amyotrophic lateral sclerosis, a PDTA between the AOUI and the ULSS 20 of Verona has been signed which concentrates on diagnosis in the AOUI and follow-up in the ULSS 20. ■

2. Cisco: Connected Health vision

DR. JENS MORTENSEN
Director for Europe,
the Middle East, Africa
and Russia,
Cisco Systems,
Denmark

Healthcare in the twenty-first century presents enormous challenges. Populations are growing, people are living longer. Many of these patients are living with chronic illnesses that require ongoing care. Compounding this problem is the widespread lack of skilled caregivers and the increasing cost of providing care. For people living in rural areas, the situation can be even more challenging, as rising travel costs can make it even more expensive to seek care.

With the right technologies in place, you can readily address your most pressing concerns: advancing quality initiatives; improving access to care; keeping costs contained; and ensuring staff productivity Our goal is to help you find the solutions you need to deliver the best care possible.

Connected Health: Inspiring New Connections

At Cisco, we are working to improve healthcare by changing the way people connect with each other, access information, and collaborate. Cisco®Care-at-a-Distance solutions give patients, clinicians, hospitals, payers and life-sciences researchers better ways to communicate, share information, and interact in real-time. The result is more efficient healthcare environments, which can lead to improved patient experiences. Our vision is a Connected Health ecosystem that dramatically improves access to care, contains costs, and boosts staff productivity.

When you make it easier and more convenient for clinicians to collaborate, you can improve both the timeliness and quality of care delivered. Cisco Care-at-a-Distance solutions can help transform the healthcare industry by providing a new access model for healthcare and new cost containment models for providers and payers.

Think of your network as a platform for delivering outstanding care. Use it to offer state-of-the-art care to patients independent of their location. Cisco Care-at-a-Distance solutions help optimize your network so you can respond to the latest healthcare challenges and empower your staff to better serve patients.

Cisco solutions enable:

Flexible, comprehensive communications: Utilizing Cisco Unified Communications, TelePresence, instant messaging, web-based collaboration, and leading-edge video conferencing, your staff can quickly share information and work more efficiently – and physicians can meet person-to-person with remote patients and their peers.

Enhanced collaboration: Video conferencing and web-based information sharing make it easy to work with colleagues in other locations, review patient cases, and provide distance learning.

Reduced costs: By raising productivity, minimizing the need to transfer patients, and remotely accessing the expertise of specialists, you can realize savings while delivering the highest quality care.

Increased productivity: Enabling your staff to access information and services across any device and location can help you maximize productivity and free up time for focusing on patients, wherever they are.

At Cisco, our Connected Health vision puts the human network effect to work for you by helping you deliver care when and where it is needed. We enable you to serve a more dispersed and diverse patient base, encourage collaboration, improve communication, and reduce costs. We enable the productivity and efficiencies that will keep you competitive for years to come. ■

3. Essence Smart Care Solutions

DR. HAIM AMIR
President of the
Essence Group,
Israel

Living Independently with Essence Smart Care

Better living is getting the care you need in the comfort of your own home. Essence Smart Care offerings were developed with the goal of revolutionizing the quality and efficiency of care services for the growing elderly population. Based on a personal emergency response system, Essence Care@Home™ solution enables families to be confident that their dear ones are cared for, while the elderly population and chronically ill patients can maintain their independent lifestyle. This is an opportunity for care providers to offer a better way of living,

I am the Founder, President and Chief Executive Officer of Essence. I come from Israel, a small State that developed for the first time in history a Global Social Health System. My Essence, my highly dedicated team of professionals and I are working very hard to provide the best home-care technological solutions to help all the people that are suffering around the world.

In the past years, we have been able to develop many interesting processes that allow us to give to the human population high quality and simple solutions to complex problems. I always remember my mother Rina, a strong woman leading my four brothers and myself, suffering during her final years from a tremendous dementia. I am quite sure that many of you, present here today, are familiar with this catastrophic situation and can understand my decision to produce the technological devices that my company is offering to patients all around the world, helping them and their families.

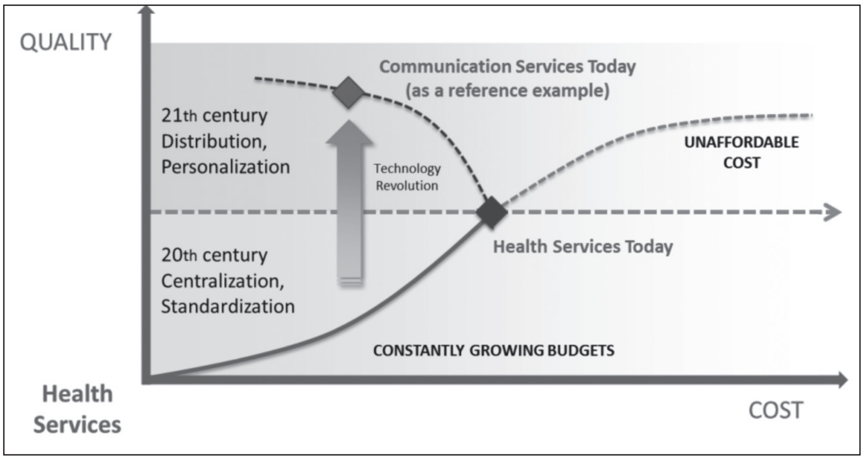
Expanding from security into health was a natural move for me. I am sure that the integration between health, industry, engineering research and the economy that we have achieved in Israel is a very good platform for our future collaboration and I want to offer you today to work together and to implement the Global Social Health System.

The 21st century's advanced and accessible health-care services have greatly contributed to the growing life expectancy of the world population, in particular in developed countries. This trend is already a fact in terms of the high ratio of elders (65+) in the total population which, it is predicted, will double within the next 15-20 years.

Most of the elderly population suffer from one or more chronic diseases and as a result require frequent health-care services. Governments are challenged to stabilize their growing health-care budgets but at the same time are required to provide high-standard health services and continuously improve their quality of service to the public.

Essence strongly believes that a major part of the solution to this situation is the ability to detect early signs of worsening health conditions or potential dangerous situations in order to reduce the number of days of hospitalization and/or prevent the need for advanced and costly health treatment.

The Impact on the Public Sector: Reversing the Trend



The modern concepts of telecommunications, security, research and development, education, and the principles of the health level of the population have to be discussed together by the experts of each country and proposed to governments as a standard for prevention, diagnosis, treatment, rehabilitation and monitoring for patients all over the world.

Essence is working on the development of next generation Telecare solutions for unlimited numbers of patients and is offering you to participate with us in this important mission. Our solutions will give the opportunity to millions of persons and their medical doctors and nurses to ameliorate their quality of life and their way of coping with their illness. Our work will help to remove the borders between nations, religions, and geographical areas and allow the human population to live in peace and ameliorate quality of life.

Being here with you today is an exciting opportunity for me and my experts to envision a new way of all of us working together. I am delighted to share our vision and offer our solutions, our ideas and our dedicated help to work together and build the platform from which we can make a better life possible for millions of people around the world.

I would also like to invite you to visit Israel and the Essence Group, promising to be your Cicerone when you decide to come.

FRIDAY 22 NOVEMBER

FOURTH SESSION

THE ELDERLY PERSON WITH NEURODEGENERATIVE ILLNESSES

1. The Protection of Elderly People with Neurodegenerative Illnesses

FABIO CEMBRANI
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1. Introduction

The subject that was entrusted to me by the organisers of this twenty-eighth international conference is not in the least simple if, naturally, one wants to address it in a rigorous and constructive way and, above all else, with the wish to shoulder our own responsibilities without retreating from adopting a clear stance on the great social issues and the epochal transformations that are now underway.

The difficulties are linked to many factors. Not only because of the diversity of the models by which the governments of many industrialised countries have outlined their long-term care (LTC) policies in order to provide a response to disability and an absence of self-sufficiency and because of the international economic crisis which runs the risk of calling into question the idea of solidarity which seemed to be a bulwark common to all the constitutional democracies, but also because, if we look at my country, other very critical elements have by now entered the scene after moving beyond the horizon some time ago. In addition to the enormous public deficit (by now 2,000 milliard euros) run up by a political class hitherto especially attentive to obtaining electoral support and little concentrated upon the interests of the weakest, from an inter-generational perspective as well, our times are marked by social poverty which is having negative consequences for the right to health, as indeed emerged from the recent dossier of Caritas in Italy (health-care poverty has increased in seven years by 97%), by youth unemployment, by a weakening in the structure of the family which has always been the fulcrum of our welfare system, and the by the existence of no longer sustainable regional deformities because of the absence of a standard model, albeit of a minimal character, of care for the very many people who are not self-sufficient. These are deformities that are at the origins of a strong inequality in the level of the coverage of need by public services and which dramatically call into question, unfortunately, those ideas of equality and solidarity of the system of social security that were subscribed to by the fathers of the constituent assembly as early as 1948, shortly after the end of the Second World War.

This is not the place to attempt to engage in a comparative examination of the various models with which, at an international level, what should be seen as an authentic social emergency of the third millennium should be addressed. I will confine myself, therefore, to exploring the Italian situation in order to perceive the critical aspects where delay is no longer possible as regards political intervention in the sphere of choices that are certainly courageous, but not ones involving compromise because transversal cuts directed towards reducing the public deficit cannot be allowed to have repercussions on the rights of the citizenry and the rights of the most frail. As long as, that is to say, one wants to continue in the direction indicated by our Constitution: that of living in a good and right way within institutions that are able not only to respect but also to promote the inviolable rights that are written into the human person.

2. Some Statistical Data to Contextualise Today's Problems and the many Critical Realities of Tomorrow

The ageing of the population is a phenomenon that affects all industrialised countries even though infant mortality continues to be a great problem in the poorest countries of the world. Our Central Statistical Institute (ISTAT) estimates that the part of the national population where there will be concentrated the greatest need for care – those of the age of eighty and over – will increase from 6% in 2011 to 15.5% in 2060, and that by the year 2030 these people will amount to 7.7 million with an accompanying increase in the number of individuals who are not self-sufficient: the number of such people will increase from the present about 2 million to 3.5 million (Zuccatelli and Lattanzio, 2011). ISTAT, through a multi-scope survey carried out a few years ago which was updated in 2011 (a survey carried out through the method of telephone interviews which, it is certainly the case, did not allow objective data and which has very great limitations given that, for example, it did not take into consideration disabled children of the pre-school age) estimated in our country the presence of 2.6 million people with disabilities to which should be added the approximately 161,00 people who are not self-sufficient who live permanently in residential institutions. These projections, however, appear an underestimate if one looks at other sources of information on the Italian situation. Indeed, CENSIS estimates that in our country there are 4.1 million individuals who are not self-sufficient, most of whom are over the age of sixty-five.

These statistical sources tell us, therefore, that in Italy the absence of self-sufficiency is a planet that is only in part known about, estimated numerically still in presumed terms given that the number of these persons is said to be between 2.6 and 4.1 million, constituting, whatever the case may be, a percentage that is by no means small of the population of Italy. From this comes the first critical element: the Italian system of welfare is characterised by a widespread dispersion of sources that provide information which apart from some local examples (Cembrani *et al*., 2013), do not allow us to have certain and updated data directly and immediately on the number of, the characteristics of and the needs of people who are not self-sufficient. This is a critical element that can in part be overcome by utilising other statistical sources and more specifically the prevalence data provided by the European network: the European Union Statistics on Income and Living Conditions or EU-SILC. This authoritative source tells us that apart from Austria, where for that matter the level of disability was much higher compared to that of other European countries, the trend of people over the age of sixty-five who in Europe have grave limitations to their autonomy has been constantly and continuously increasing and that the part of the population with the highest level of increase as regards this development is specifically that of those in their eighties and over (Iagger *et al.*, 2011).

The consequences of this authentic transition in epidemiological terms and their impact on the incidence of neurodegenerative diseases are, unfortunately, known about. The number of these sick people is destined to increase steadily in all advanced Western nations: the number of people with dementia (estimated at 35.6 million), indeed, is destined to double every twenty years and this means that in the year 2050 these sick people will number 115.4 million ((World Alzheimer Report, 2009). If we examine the case of Italy, people with dementia, who it is estimated numbered about 800,000 a few years ago, will become 1.13 million in the year 2020 (Di Carlo et al., 2002), when we take into account that this diseases afflicts about 20% of people over the age of eighty-five with a percentage that rises above 30% in people over the age of ninety (Ferri *et al.*, 2005). In parallel with this development, the social costs of treating and looking after these sick people which, at a world level, are estimated at being 600 milliard dollars, albeit with the point that almost 90% of this sum is met by industrialised Western countries where, however, only 46% of patients with dementia are to be found (World Alzheimer Report, 2010). As regards this heading of expenditure, it is calculated that there will be an increase of 85% by the year 2030, even though it should be said that in our country 71.4% of costs, estimated at being about 60,000 euros a year, are met by families and only the remaining sum is met by the national health service (CENSIS, 2007). For that matter, these calculations do not take into account the costs of family-provided care in terms of loss of health because it is estimated that a percentage that varies between 40% and 75% of care providers suffer from significant disorders and that 15%-32% of these people develop grave depressive disorders (World Alzheimer Report, 2009). In the United Kingdom it is even calculated that the social costs generated by those who are involved in the provision of care are greater than those produced by illness and that the overall costs of dementia are greater than those for cancer and tumours even though the research in this sector receives funds equal to a twelfth of those allocated to the latter.

The steady increase in the number of elderly people who are not self-sufficient is in contrast, at least in Italy, with a gradual weakening of family networks which no longer have the characteristics and duration that they once had and that it has been so to speak obligatory to involve in the provision of home care over 840,000 immigrants, with little training and often employed without a legal contract. This situation has been brought about by an extension in the length of the working life because of a welfare reform applied to our country in an attempt to curb expenditure on welfare (pensions are responsible for 16.1% of GDP), because the participation of women in the labour market was until a few years ago on the increase even though unemployment levels today have become an authentic social emergency, because the need to have two incomes has by now become a common characteristic of very many Italian families, because atypical and not very numerous family structures have increased, and because, last but not least, of the increase in average age when a family decides to have children, as a result of which women find themselves at the same time at work, with the tasks of a parent and also the responsibilities of providing care to relatives who are not self-sufficient.

3. The Juridical Foundations of Social Solidarity and Freedom from Want

Before entering the question of the many problems which healthcare professionals encounter every day in their activities involving diagnosis and treatment, one should take a step backwards to try to indicate the juridical elements that give shape and depth to that freedom which Franklin Delano Roosevelt referred to as freedom from want. This President of the United States of America, on 6 January 1941, in a speech to Congress on American security prefigured a world founded upon four essential freedoms, including amongst them, together with freedom of speech and expression, religious freedom and freedom from fear, also freedom from want. A few months later, on 10 June 1941, the liberal William Henry Beveridge was invited by Winston Churchill to be the head of an inter-ministerial committee on systems of social insurance and welfare services. On 20 November 1942 Beveridge, at the end of the deliberations of the committee, presented the report Social Insurance and Allied Services in which he took up the subject of freedom from want and identified five great woes of humanity (poverty, illness, ignorance, squalor and idleness) and posited measures to combat them: amongst these was the creation of a national health service for the whole population. This idea of Roosevelt, which was developed in England by the liberal William Henry Beveridge with the creation of the National Health Service, found major resonance in Italy as well because of the jurist Pietro Calamandrei, a strong supporter of those social rights which then found full recognition in the Constitution approved in 1948 and more in particular in its article 38 which outlined our welfare system: a system that was then enacted by the Italian legislature through social insurance and welfare protection. Whereas the first covers certain well defined risks (accidents at work and occupational illnesses, common illnesses, unemployment and invalidity) which are covered by the making over of a obligatory contribution paid in part by the worker and in part by the employer, welfare protection, on the other hand, concerns everyone, independently of their age, their income resources, whether they have a job, and thus of the regular payment of a contributory sum.

As regards welfare protection, it should be said that our parliament gave form and shape to this through repeated legislative measures starting in the 1960s. For reasons of time, I cannot examine them here even though I cannot fail to observe some critical features.

A first critical element that one perceives when looking at these very numerous provisions is their large number and the lack of an organising principle, with the exception of privileging a delegating welfare system based first and foremost on money transfers (or cash transfers) which explains why our parliament over time has acted in a disordered way, often pushed forward by corporative interests expressed by certain interests representing disabled people. A second critical feature concerns the way in which the Italian legislature has acted in this field, breaking down disability into different categories on the basis of anachronistic nosological criteria: in our country disability has thus encountered an equally equivocal taxonomical differentiation and has become an idea that it is difficult to express in an explicit way because it has been fractionated on an aetiological/categories basis. It is for this reason that still today there are the sense disabled, the physically disabled and the mentally disabled: amongst the first the blind and the deaf and dumb, amongst the second the civilian invalids, people with amputations, people with more than one amputations and people with grave movement limitations, and amongst the third the mental invalids and intellectually disabled to whom, more recently, have been added the handicapped as well. A further critical element, which increases diversity amongst equals, is the provision for these different categories of people in need different levels of economic support: we need here only point to the fact that the sum for accompanying that is envisaged for those people who are completely blind is 846.16 euros a month for twelve months of the year whereas that envisaged for civilian invalids is 499.25 euros for twelve months of the year, with the exception of some autonomous Provinces which have introduced a thirteenth monthly payment. A fourth critical element is that of having allowed these money transfers not to be modulated on the basis of the income of the person or family and in the case of people disabled as regards their senses to have allowed them to be made over simply because the person is disabled and thus also given to people who are perfectly integrated into the world of work, their families and society. A further critical element which has demonstrated all of its crudity in recent years is that the fine premisses of the spending review directed towards improving the efficiency and the efficacy of the state machine in the management of public expenditure have still not been able to achieve a structural reform of our welfare system, unless one wants to emphasise the extraordinary assessment plans promoted by the then Chancellor of the Exchequer, Giulio Tremonti, to unmask the so-called ‘false invalids’ and the transfer to the insurance and pension body (INPS) of those functions which until a few years ago were carried out by various parts of the national health service.

4. Italian Long-term Care Policies

Italy is the only one of the great European nations which has not yet implemented an overall and structural reform of long-term care (Zuccatelli and Lattanzio, 2011), even though this reform has been announced on a number of occasions with mandates given by parliament to the government which, however, unfortunately, have never been carried out. This undertaking was not even carried through by the previous government of technicians led by Mario Monti, a government which seemed to enjoy a broad immunity as regards electoral pressure. For this reason, there does not exist in our country a uniform model for the protection of that elderly part of the population that is not self-sufficient but instead there coexist policies which vary from region to region and from commune to commune with broad and deep differences which probably grew greater with the decision taken by the Berlusconi government to eliminate, for reasons involving financial stability, the National Fund for Absence of Self-Sufficiency. These are differences that lie behind the existence of many Italys and which have effects on the fairness of the system and also create strong and unacceptable inequalities between equals.

Lets us try to analyse these but we should do this remembering that the measures adopted by state authorities for elderly people who are not self-sufficient are substantially three in number: (a) money transfers of a welfare character (cash benefits); (b) socio-healthcare (ADI) and social (SAD) provisions involving assistance at home; and (c) measures involving residential help.

Public investments allocated by Italy to these measures is certainly not high if related to our gross domestic product (GDP). The number of money transfers through payments registered in the year 2010 by the General Accounting Office of the state was about 1.8 million with an overall expenditure that amounted to about 0.8% of GDP (total value of goods and services produced) and it is posited that it will reach in the year 2060 1.5% because of a further ageing of the population. To this economic commitment should be added that category of expenditure which involves the healthcare component of residential homes, self-residential homes and homes proper that are provided to people who are not self-sufficient – this expenditure, in turn, constituted once again in the year 2010 0-86% of GDP, and that involved in help of a socio-welfare kind that is provided to disabled and non-self-sufficient people (2.9 milliard euro), for an overall expenditure which reached in the same year 1.86% of GDP.

This percentage figure is not in the least exorbitant and demonstrates how our country does not allocate major sums under this heading of expenditure which is equal to that expended on the military sector according to the estimates provided by the SIPRI (the Stockholm International Peace Institute), given that in the year 2012 Italy spent over 26.46 milliard euros on its military machine. However it is also true that above all else in the period 1980-1997 our level of social expenditure steadily increased, that 61.5% of this expenditure involved cash benefits (this percentage decreases to 45% in the rest of Europe) and that the public financial allocation for these subventions is the highest not only within the European Union but also amongst the countries that belong to the OECD.

To sum up: in Italy the social cost of helping people who are not self-sufficient through cash benefits is greater than that required to finance the public service for people who are not self-sufficient. For this reason, our welfare system is of a substantially delegating character and still uses the family as a fulcrum for looking after these people with the further consequence that public services are very weak because of the steady reduction in the national funds for social policies as well: in the year 2007 the sum allocated under this heading of expenditure was 1,339 milliard euros whereas in the year 2011 this sum decreased to 339 million euros after the elimination of the Fund for the Absence of Self-Sufficiency (400 million euros in 2009 and 2010) which took place with the stability law of 2011.

4.1. Cash Benefits

These are cash benefits that constitute (Chiatti *et al.*, 2010) the most important system of support for elderly people who are not self-sufficient, both in terms of public resources involved (about 1.1.% of GDP) and the breadth of the category that has access to them (1,800,000 people). They are paid over: (1) as a subvention for accompanying envisaged both for civilian invalids who are not self-sufficient (499.27 euros a month for twelve months of the year) and for people who are completely blind (846.16 euros for twelve months of the year); (2) care payments whose size varies from place to place even though many regional governments of the South of Italy have not invested in this field; (3) vouchers and other cash payments provided by those communes who have money available for this purpose, for example for projects for an independent life.

The payment for accompanying is a cash benefit of a welfare kind, which cannot be transferred, and is not connected to obligatory contributions or at the present time to personal or family income, whatever that may be. It was introduced in Italy by the law of 11 February 1980, n. 18 ‘indemnity of accompanying civilian invalids who are totally disabled’) which was then modified by the law of 21 November 1988 n. 508 (‘supplementary rules as regards economic help for civilian invalids, civilian blind people and the deaf and dumb’) and by the legislative decree of 23 November 1998 n. 509 (‘rules for the revision of the categories of disabilities and invalidity illnesses, as well as the benefits envisaged by the existing legislation for the same categories, according to article 2, section 1, of the law of 26 July 1988, n. 291’).

The category of people who are recognised as having this right is large: at the end of the year 2012 there were 1,800,000 accompanying subventions allowed for people who were not self-sufficient and their cost overall was above 13.5 milliard euros. The trend was an increase of 60% between 2002 and 2009 given that every year there was an increase in the number of such subventions of about 100,000, which amounted, according to the data provided by the General Accounts of the State to a little below 1% (0.8%) of GDP, a figure, however, that is destined to double by the year 2060. This is not very much when compared to the expenditure on pensions which amounted to 16.2% of GDP, with an upward trend leading in 2013 to an estimated 5.7 milliard euros.

If we proceed to analyse the data that are available it emerges that the proportion of beneficiaries compared to the overall resident population of the same age and sex remains substantially stable until the age of 65 but then rises rapidly with the next age bands, even if one takes into account that as regzrds people over the age of ninety the level of bestowal of this right is about 34% for males and about 52% for females.

The level of uptake of this subvention of accompanying is not however linear if we analyse the individual regional contexts. At the top of the list is the region of Umbria where one person over the age of sixty-five in every five of the same age receives a subvention of accompanying. This is followed by Calabria (18 in every 100 elderly people), Campania (17.1 in every 100 elderly people), Sardinia (15.9 in every 100 elderly people) and Abruzzo (14.6 in every 100 elderly people), while at the end of the list is to be found the Trentino Alto Adige region (7.8 in every 100 elderly people).

This broad lack of homogeneity in the level of uptake of the subvention of accompanying demonstrates either a different distribution of the regional incidence of an absence of self-sufficiency or, alternatively, the existence within our country of a lack of fairness in levels of access to this economic benefit. I am not able to analyse the reasons for this in a complete way, even though some causal factors can enable us to understand this diversity. Because in the regions of the South and those of the islands the enjoyment of cash benefits has always been used, beyond the fraud perpetrated to the disadvantage of the state, as a shock-absorber for unemployment; because the number of beds in residential institutions vary from region to region; and because of the lack of precision of the rules and regulations in this field which have been listed above and the difficulties in interpreting them. These rules and regulations point to the conditions which allow a bestowal of this right, where these are identified with 'physical or mental disabilities', their consequences being indicated, alternatively, as 'an inability to walk or move around without the permanent help an accompanying person' and/or the need for 'continual assistance… there not being an ability to carry out the normal actions of life'. They also refer to the administrative decisions that justify such help: whereas law n. 18 of 1980 excluded 'grave civilian invalids admitted free of charge to institutions', the two reforming laws as regards these cash benefits of 1988 confined the right to citizens resident in the national territory as long as these people were not the receivers of 'similar subventions granted for forms of the invalid state caused by wars, work or service', albeit with the option remaining to 'opt for the most favourable form of help'.

The regulatory indications, unfortunately, were not formulated in a clear way as regards the definition of impairment. In law n. 508 of 1988, similarly to law n. 18 of 1980, the reference is to 'physical and/or mental disabilities' caused by a 'total inability', without any distinction being made as regards the age of the person. The legislative decree n. 509 of 1998, on the other hand, mentions a different parameter for people not yet of working age (minors) and for people over the age of sixty-five, namely 'persistent difficulties in carrying out the tasks and functions specific to their age'.

Here certain clarifications are required in order to characterise through their definition the problems that are encountered in assessing need not so much with reference to 'inability' (pleonastically receiving the adjective 'total') as to 'persistent difficulties' which the legislative decree n. 509 of 1988 correlates not so much with the ability to express a capacity for work but, more appropriately, with 'functions specific to their age', even though limited to people who have not yet reached the working age or no longer belong to it.

These two situations (total inability and persistent difficulties) produced by physical and/or mental disabilities have to be explored better not so much at a taxonomical level as, instead, with reference to what defines them: in other words, in relation to what elements they should be explored, before entering the vortex of problems that are encountered in their assessment.

As regards 'total inability' the situation is sufficiently clear. It is defined as a conceptual paradigm closely connected with the inability to work of the state of being an invalid entitled to a pension because it has to be examined as a consequence of 'permanent functional damage' as cited in article 1 of the legislative decree n. 509 of 1988, with a use of the medical-legal set of criteria expressly indicated by the legislative decree n. 509 of 1988 and the indications expressed in the tables of the decree of the Ministry of Health of 5 February 1992: with reference, therefore, to the impairment as regards work produced by each disability and/or by their set of realities involving being an invalid, acting together with and/or coexistent whatever the case may be, with reference to a capacity for generic work. The inability, therefore, is defined as the loss of a capacity to work.

As regards, instead, the 'persistent difficulties', the problems of interpretation remain as open (and as unsolved) as ever: the regulations that have been referred to above identify the two conditions that are needed but which are not sufficient (prerequisites) at the basis of the subvention of accompanying and they are seen, separately, as total inability and persistent difficulties and refer these last, albeit solely to people under the age of eighteen and over the age of sixty-five, not to impairment as regards work as, instead, the capacity to carry out 'the tasks and the functions specific to their age'. These are tasks and functions, however, that are not explained by the legislature which seems, therefore, to intend them in a way that is not at all distinct in both age bands, with a defect of clarity that is at the origin of that short circuit at the level of interpretation which, when understood correctly, ends up by equating them with (and confusing them with) the 'daily actions of life' which constitute, together with the ability to walk and move around, one of the two conditions which justify the bestowal of this right.

And with a whole series of inconsistencies which should be commented upon. A first inconsistency derives from the rigidity of 'tasks' and 'functions specific to their age' referred to two large and heterogeneous categories of the population, that is to say minors and people over the age of sixty-five, which does not allow distinctions to be made. The tasks and functions specific to age of a neonate of a few months of age cannot be confused with those of a teenager, in the same way, for that matter, as the tasks and the functions specific to age of a person over the age of sixty-five who is still working cannot be those of a person over the age of hundred. A second inconsistency is produced by the already referred to defect as regards explanation which ends up by confusing (equating) the tasks and the functions specific to their age with the daily activity of living, which is a reproduction in Italian of the terminology of Anglo-Saxon rehabilitative medicine and in the assessment of which certain simple multi-axes can be used at will: these may constitute the basis of a hypothetical pyramid which, more extensively, should correspond in a flexible and not rigid way to these tasks and functions specific to age, although it is not able to define them in a complete way. A third inconsistency, lastly, amounts to one of the most evident paradoxes that characterise today our system of assessment. Impairment as regards work is decided upon through the rigorous application of the rules laid down by the legislative decree n. 509 of 1988 which, in the interplay of acting together and coexistent disabilities and the envisaged exemptions, allows a level of discretion as regards the decisions made on the percentages of a state of being an invalid that are obtained through the application of the tables approved in 1992 of five percentage points (more or less) as regards jobs in conformity with the aptitudes of the individual concerned, the specific kind of work that is engaged in and the technical-professional training of that individual. But the tasks and the functions specific to the age and the related persistent difficulties are subject to a broad area of uncertainty at the level of definition based upon a dizzy legislative void which, in lending itself to free interpretation, ends up by creating in our country what are phenomena of social unfairness.

This void has been filled on a number of occasions by certain attempts to interpret the rules which ended up by creating the opposite effect, that is to say producing other confusions at the level of definition in a sector of protection which requires a broad structural reform that in reality can no longer be delayed. Here one is referring in particular to three circulars of the Ministry of Health which were issued, respectively, on 4 December 1981, 28 September 1992 and 27 July 1998. By the first circular of 1981 (prot. n. 500.6/AG. 927-58-1449), the Ministry of Health sought to clarify the real character of the two conditions alternatively envisaged for the right to have a subvention for accompanying albeit without addressing, as was the case in the subsequent circular, the prior question of the tasks and functions specific to age. In this circular it is made clear that 'they are unable to walk and move around those invalids who cannot walk or move around even with the help of orthopaedic aids' and that 'by daily activities of life is meant those elementary activities which a normal individual of corresponding age performs every day and which makes the disabled person who is not able to perform them in need of assistance'. By the subsequent circular of 1992, the same Ministry of Health identified the daily activities of life as 'those elementary activities and also those which are relatively more complex not connected with work functions directed towards that minimum of average needs of life relatable to a normal individual of a corresponding age, so as to allow individuals who are not self-sufficient conditions of existence which are compatible with the dignity of the human person'. Compared to the previous circular, this circular extends the idea of daily activities of life, ending up by placing in this category also those functions which are 'relatively more complex' and which, although separated from impairment as regards work, allow a person to have an existence which is anyway dignified.

In the circular of the Department for Prevention of the Ministry of Health of 27 July 1998 (prot. n. DPV.4/H-F1/643) an attempt was made, on the other hand, to address the question of 'persistent difficulties' in a way that was totally inconsistent with the broad elaboration at the level of doctrine, even though with the declared aim of 'simplifying the world of the assessment committees' and solving the major problems produced by the ending of the giving of percentages to impairment in terms of work to individuals over the age sixty-five and which, because of the fragmentary nature of the rules and regulations, were at the origin of extensive difficulties both in the field of the provision of walking aids and other supports and in the field of exemption from having to pay a part of the costs for pharmaceutical or health-care products. This circular directed towards offering interpretations, in its attempt to remedy the problems that have been created by or which had escaped) the legislature, so to speak graded the 'persistent difficulties' in three levels of intensity defined by the adjectives 'light' 'medium-grave' and 'grave', deduced 'either on the basis of the activities or proceeding to a new medical examination', with reference to the percentage measurement of the impairment in terms of work: this was an operation that was totally out of place which in its apparent simplicity produced totally deleterious effects at the level of the correct interpretation of the rules and regulations, confusing thereby inability in terms of work (a 100% invalid state) with grave persistent difficulties.

The instructions of these circulars of the Ministry of Health, therefore, further muddied the waters and have produced major problems as the level of application despite the hoped-for simplification, for the further reasons that (a) they did not explain what the 'daily activities of life' are in relation to which there must be an assessment of the 'persistent difficulties, although they are at times defined as 'elementary activities' and those activities which are 'relatively more complex… directed towards meeting that minimum of average needs of life that can be related to a normal individual of a corresponding age'; (b) they do not indicate what are the multi-axes to be used in the assessment of these 'persistent difficulties' and whether, as in the case with impairment in terms of work, there exists or otherwise a threshold of exemption, the overcoming of which bestows the right to a subvention of accompanying; (c) they make banal and short-circuit the problems created by the legislature by grading the 'persistent difficulties' in relation to the level of impairment as regards work which is determined in percentage terms.

Another cash benefit provided to elderly people who are not self-sufficient in the form of a money transfer is the care cheque which, however, is subject to a different set of rules and regulations and bestowal within the individual regional contexts of Italy, having been negatively affected by the reduction in the National Fund for Absence of Self-Sufficiency (275 million euros) which took place with the last stability law. These funds, which are given to the regional governments on the basis of the resident part of the population of an age of seventy-five or over and of criteria utilised for the distribution of the National Fund for Social Policies, are in fact amply insufficient in dealing with the social emergency of people who are not self-sufficient and in reversing the tendency of placing them in institutions and in fostering them staying in their homes. Indeed, every local reality has in fact made a virtue of a necessity. Thus the autonomous Province of Bolzano provides care cheque to people in need of help from third parties in order to deal with daily life within the context of assistance and care to an extent greater than two hours a day in an average week for at least six months. The Regional Government of Veneto replaced it in 2013 with the Home Care Service, known in Italian by the acronym ICD, where there are five kinds of ICD, one of which is an innovation inasmuch as it is for people with grave needs at the level of assistance during every hour of the day. The Regional Government of Piedmont extended it to all people with grave disabilities under the age of sixty-five and its value varies according to the severity and the needs of the person concerned, not being, however, more than 800 euros a month in cases of a low intensity of assistance; 1,100 euros a month in cases of medium intensity; and 1,350 euros in cases of medium-high intensity (which can be increased to 1,640 euros for people without a family network). A similar situation has also been adopted by the Regional Government of Trento where the care check was introduced as early as 1997, even though that Provincial law was then repealed and replaced by another law which identified four levels of severity of absence of self-sufficiency with sums between 100 euro a month for the first level of severity and between 500 and 1,100 euros a month for the fourth level of intensity according to the economic indicator (ICEF) of the applicant.

A third form of economic support for elderly people who are not self-sufficient is that provided by communes by means of a voucher and socio-health-care vouchers: as regards this form of social expenditure, however, we do not now the overall sum paid by our country, even though we know that there are very low levels of coverage in the regions of the South and the islands. In Calabria, for example, 323 euros a year were spent on the beneficiary whereas in the autonomous Province of Trento this cost reached the sum of 6,491 euros compared with a national average of 1,125 euros.

4.2 Home Services: Integrated Home Assistance (ADI) and the Home Assistance Service (SAD)

In our country the presence of these home services is not only limited but also, unfortunately, not at all homogenous from local area to local area.

If we look at integrated medical-nursing home care (ADI) which is defined by the World Health Organisation as 'the possibility to provide at the home of the patient those services and those instruments which can contribute to the maintenance of the highest level of wellbeing, health and functioning', the most recent published data (Chiatti *et al.*, 2012) demonstrate for the year 2009 a slight expansion of the platform of people covered by this service provided by all the local health-care companies (with the exception of the area of Locri), accompanied, however, by a decrease in its intensity in terms of the number of hours provided for each individual case for which responsibility is taken. For that matter, only 3.6% of elderly people resident in our country have received this service for a total of nineteen hours of care a year for each case; with a slight increase of the platform given that in 2007 the percentage was 3.3.% despite the objective indicated by the Ministry of Health of reaching 5.06% (indicator of the taking of responsibility for elderly people as regards the service of integrated home care: percentage of elderly people receiving integrated home care compared to the total number of elderly people in the population over the age of sixty-five), even though, as has been said, the number of hours of care has declined, passing from 22 to 19. With ample differences between region and region if we consider that, once again in the year 2009 the level of coverage and the intensity of the service were very heterogeneous. The highest levels of coverage were recorded in Emilia-Romagna (8.3%), in Friuli Venezia Giulia (7.7%) and in Umbria (7.6%): in this last region the intensity of the service reached an average of 28 hours every year, in Emilia-Romagna 21 hours every year, and in Friuli 7 hours every year. The lowest levels, on the other hand, were registered in Valle d'Aosta where, however, 40 hours of care were given to each individual case, in the autonomous Province of Trento where the average hours of care each year were 25, and in Sicily where the average number of hours for each individual was 19. The region with the highest intensity of such care was Molise (55 hours) where, however, the level of coverage registered was very low (2.4%) and 0.4% lower than in the period 2001-2008.

As regards the social assistance (SAD) assured by communes or mountain communities, for some autonomous Provinces the situation does not involve encouraging data. The most recent data published by ISTAT demonstrate that in 2007 only 1.7% of elderly people over the age of sixty-five are supported at home by this form of service, with a small percentage fall since 2006 (0.1%), even though with a very slight increase in costs – the average costs rose from 1,645 euros in 2006 t0 1,761 euros a year for each individual, albeit with major difference from region to region (with the highest levels registered in the autonomous Province of Trento of 4,219 euros every year and the lowest levels registered in Abruzzo of 818 euros a year). If we consider this service, the differences between the North and the South of Italy are specially significant: one need only observe that the regions of the North-East have a level of coverage as regards this service activated by the communes of 96.1%, whereas this percentage declines to 88.2% in the islands and to 83% in the mainland South.

Another interesting comparison related to the level of integration between the ADI and the SAD – a level which is at a level of 100% in the region of Veneto and that of Umbria where people who are not self-sufficient and for whom responsibility has been taken by the public services enjoy both these services, but which falls to worrying levels in Sicily and in the autonomous Province of Trento where the levels are respectively 3.4% and 4.9%. This demonstrates the lack of coordination and shared direction, at least as regards the year 2007, between social policies and those policies implemented by health-care structures. When we look at the national average the situation does not change: an analysis of those people who belong to both home services shows in Italy an average integration of 47.4%, with very low averages in the islands where the level of integration is a little above 4%.

4.3 Residential Services

Residential care has a marginal role in our country in LTC policies if we consider that only 2% of people over the age of sixty-five live permanently in health-care homes (RSA), in socio-health care homes (RS) and in care homes (RA), and this at a time when the European average is much higher (5%).

In the context of the present 120,000 residential and semi-residential beds, the National Committee for the Definition and Updating of the LEA estimates that there is a need in our country for 496,000 beds, with the result that at the moment there are over 250,000 people who are not self-sufficient at home who require not only accommodation services but also health-care, nursing and rehabilitation services that are provided by their family networks (and by non-family caregivers) when we take into account that only 527,000 (3.6%) elderly people over the age of sixty-five are followed by ADI where the European average is 7%.

If we look at the statistical data that analyse region by region the number of beds for every thousand elderly people, the situation is troubling: the highest levels are to be found in Trentino-Alto Adige (96 RSA with 40.4 beds for every 1,000 elderly people for a total in the autonomous Province of Trento of 4,338 beds and of 3,346 beds in Bolzano); the lowest points are in Campania and Basilicata where the level is below zero given the existence of 563 beds distributed in 18 RSA and 191 beds in 5 RSA. In our country one moves from contexts where long-term stays and institutionalisations are very frequent such as Lombardy and Trentino Adige and others such as Campania and Basilicata where the use of homes with a high intensity of care (RSA, 0.1% and 0%) and post-acute long stays (0.4%) are not frequent. The region of Lazio (Chiatti *et al.*, 2012) has a situation which is to say the least strange: in the context of a truly limited use of RSA (0.5%, the levels of long-stay hospitalisation and intensive rehabilitation are respectively 0.6% and 3.3% with a very long average stay: 82.4 days as opposed to an Italian average of 33.5 days in long stay and 38.7 days as opposed to 25.1 days in rehabilitation). This demonstrates that the shortage of beds in RSA is used to justify an extension that is not appropriate of the stay during the post-acute stage with costs that are absolutely not sustainable.

5. A Summarising Look

I will try to summarise the statistical data that have been presented by formulating some summarising conclusions.

The first conclusion is that in Italy we do not have a uniform LTC policy that is able to meet the needs of people who are not self-sufficient and to personalise action in relation to need because the service that is offered is an often inconsistent mix of cash benefits, help provided in the homes of people and residential or semi-residential policies whose results in terms of health we do not know.

The second conclusion is that Italian regions are divided by a profound gap given the strong inequalities between the richer North and the poorer South where the family-provision of care in certainly a constant and where the public services demonstrate a strong weakness both in terms of the number of people for whom responsibility is taken and to whom care is provided.

The third conclusion is that the exponential growth of the number of people who benefit from the subvention of accompanying demonstrates the prevalently cash-oriented character of our LTC policies where, as has been seen, money transfers underwent during the year 2004 and the year 210 an increase of 1.14% of GDP according to the data provided by the General Accounts Office of the State.

The fourth conclusion is that the funds for social action have undergone a net reduction and that with the elimination of the Fund for the Absence of Self-Sufficiency they are in the last line of the table summarising the public investments of the state in Italy.

6. Conclusions

The profound and epochal rapid transformations that we are witnessing, the contraction in public resources and the spending review policies that are underway in all the European States in order to correct their public debts are factors that cannot but be taken into consideration to produce that structural reform of our welfare system which has often been announced but unfortunately never implemented.

This is a reform, obviously, that must be taken in hand with the courage of action without, however, abandoning that idea of solidarity which is, and must remain, the central theme of all constitutional democracies. And not forgetting that solidarity is a demanding term not only because it evokes social ties between people and future generations but also because it is a setting into which flow not only the Christian tradition but also different cultures which share the idea of a dialectic schema which requires a mutual recognition between equals and that support that cannot be denied to the weakest people. Yet on the assumption that one wants, naturally enough, to pursue that idea of citizenship which calls on each one of us to live out our responsibilities in an authentic way with a view to achieving a better world to be left as an inheritance to our children and the future generations.

In the renewed perspective of solidarity I believe that one must move forward with the strength of ideas and with the courage to act, aware that giving more to those who are in need is a valid teaching for all seasons even though this means, for some of us, a change in approach and a retreat from the privileges of today's world. It is certainly the case that the current stage of turbulence which envelopes our personal biographies is not a good premiss but if one sees the glass, as used to be said, as being half full and not half empty, this can be an extraordinary opportunity for a structural revision of Italian policies for the protection of the absence of self-sufficiency – a protection that cannot go on being a field to be ploughed with the transversal cuts of public expenditure but looking at Europe and the good experiences which certainly exist.

If we want to go ahead in this direction we need precise choices and we need to abandon non-structural alchemies and actions. We need first of all to allocate to this sector of public expenditure greater public funds without increasing the tax burden which has by now reached in our country unsustainable levels and which runs the risk of transforming the economic crisis into an authentic social crisis, but, rather, by reallocating resources in a courageous way from other sectors of public expenditure: containing to the minimum expenditure on great works and on the military, for example, reducing our participation in international missions which have little that is humanitarian about them and military programmes to which the current government has recently allocated almost a milliard euros.

We need, secondly, to correct the traditional model of welfare which is based upon an anachronistic aetiological differentiation of disability and upon monetary transfers which conditions the weakness of public services dedicated to support for home-based help and delegation to the family of caring for its members who are not self-sufficient: these services, therefore, should be strengthened through the introduction of a work force endowed with precise professional skills and tasks, not only because the subvention for accompanying is a cash benefit that is not always used for the payment of helpers employed in a black economy when it is not, indeed, illicit, but also because the family needs to be supported and guided whereas today it is left on its own to find a solution to its problems. Investing, therefore, in the network of health-care services and those social services for home-based care in addition to the private-social sector and voluntary work, even though this could involve the person involved meeting some of the expenditure – expenditure that can always be modulated in relation to the individual's assets if one wants really to invert that tendency towards institutionalisation which today is a characteristic of welfare and not only Italian welfare.

And we also need to review the criteria for access to cash benefits on the basis not only of the economic conditions of the individuals who are not self-sufficient but by tying them to the purchase of goods and services and ones that are suitably prepared. Not providing them, therefore, solely on the basis of disability as takes place today in the case of blind people or people who are deaf and dumb but grading them according to different levels of disability as, for example takes place in France where the decision was taken to allocate public intervention to the highest needs (Colombo *et al*., 2012).

And, lastly, we need to motivate, and generate more responsibility in this area in, those professionals involved in the welfare network by creating synergies between the health-care world and the social world and developing their capacities as regards the good use of resources and the assessment of outcomes as regards health adhered to through the action that is planned and carried out. Not least because self-a referring public service is always weak.

We need, in a few words, to work together, all of us, by directing political decisions and professional conduct in terms of justice and no longer in terms of social charity, ridding ourselves of that logic which ends with the granting of a pension to an invalid, a cheque or a voucher. Interpreting, therefore, solidarity in an authentic, Christian and civilised, approach, with a way of reading things that invites us to be men and women committed to an extraordinary human mission which, as Cardinal Tettamanzi declared, invites us not to reduce human needs to a commodity and to see human relationships, an absence of self-sufficiency and finitude as characteristics of the human being highlighted in a completely special way by the neurodegenerative pathologies of elderly people, without ever forgetting to defend and promote the dignity of the human person. ▪

2. The Needs of the Family

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Preface

The family, and in particular the family relative of reference, that is to say the person who most directly and for the most time during the day attends to caring for the patient (the so-termed 'principal carer'), in large part make up for the absence of therapies that deal with the problem and in themselves perform a therapeutic role. Unfortunately, in many cases the personal, social and health-care costs that bear heavily upon the solidity of the family structure itself, associated with the absence or inefficiency of local-area services and home-based services, lead in the long term to the decision to institutionalise the sick person.

In order to value and optimise the important contribution that the family makes available to society through daily care for these sick people, it is. however. necessary to activate support services and strategies that allow the burden of daily care that is provided to be lightened and made more bearable. Unfortunately, it is often the case that institutions and services are totally absent or inadequate in the face of the numerous problems and needs of these sick people, with the result that the family does not find adequate support.

An intermediary role between the family and government institutions is played by associations dedicated to voluntary work which in large measure are created through the union of families and individuals who live or have lived with the same problems. Whereas, on the one hand, the sharing of the same condition and interchange about shared experiences can constitute a sort of 'support therapy' that is able to prevent anxiety and depression, on the other the promotion through these associations of structured initiatives involving information and education can have a positive impact both on the 'health' of the family and on the health of the patient.

To this end the Federazione Alzheimer Italia established the 'Carer Project' together with the Mario Negri Institute of Milan in order to assess the impact of structured initiatives involving information and education on the approach to, and management of, the needs and problems that family relatives habitually encounter in caring for these sick people. In addition, it has produced numerous booklets and textbooks in cooperation with Alzheimer's Disease International (ADI) and Alzheimer Europe to inform family relatives about the needs that they may come up against and to help them to address them.

The numerous needs that the family encounters in the development of the disease follow the constant changes in the needs of the sick person. During the initial stage the first symptoms appear, doubts emerge and the need grows for a diagnosis which, once it has been obtained, generates yet further doubts.

Should the Sick Person be Informed?

If the disease is at its initial stage informing the sick person of the diagnosis can allow him or her to discuss the malady and to be informed; to obtain access to help, to obtain state payments and services more easily: to understand the need for certain precautions (as regards driving or using machines); to attend to financial, commercial and legal questions: to give his or her own consent to therapies, pharmacological treatment or care; plan or communicate his or her decisions as regards the end of his or her life; to decide if he or she wants to take part in research projects and to participate actively in Alzheimer support groups.

How the Diagnosis should be Communicated

At times the carers want to provide this information but they do not know how to do this. A perfect method does not exist; each person is different. Some people prefer to be informed privately in a face to face conversation, whereas others feel reassured if they are informed in the presence of their family or of an intimate friend.

It is advisable whatever the case to understand the needs of the sick person, to ensure that or she is not opposed to being informed, to remember what the sick person knows about dementia so that his or her reaction can be predicted, to adapt the information to his or her capacities, to do so in a private and pleasant place, and to be prepared foe possible questions. It may be useful to fix an appointment with the medical doctor.

Accepting the Diagnosis

A diagnosis of dementia does not strike only the sick person: it also afflicts the whole of his or her family and accepting it can be a long process which is often accompanied by different emotions. The necessary time should be taken to adapt to the idea and someone should be looked for to whom to turn so as to be able to receive information and advice. It is essential that the sick person be not rebuked: it is not his or her fault.

What should be Done Now?

The period following the diagnosis can be extremely difficult both for the sick person and for those who take care of him or her. This is a new and worrying experience. Although, unfortunately, easy solutions do no exist, it is possible to do a great deal to ensure that the long pathway of the disease is lived through in a better way.

Taking Care of Oneself

Drawing up Positive Strategies

The strategies vary and it is the task of each person to find the one that is most suitable to the case in hand. Overall, one can say that getting worried and apportioning blame is of no use and it is more positive to address the problem or look for information and social support. Realistic goals should be set and attempts should be made until the best solution is found. One can seek to solve the problem by finding practical help, reorganising the home, and creating a routine or a different way of doing things. Or one can try to change the way of seeing oneself, the problem and its consequences. Those people who have philosophical or religious beliefs can find help in religion or their own philosophy of life. Fundamentally, this is a matter of finding the approach that works best and then living day by day.

Maintaining a Network of Social Relationships

The people who care for these kinds of patients often forgo the things they love (holidays, hobbies, work, various types of activities and contacts with friends and relatives) in order to have time and energy to devote to the person who has dementia. This is a mistake: the quality of care strictly depends upon the physical, mental and psychological health of the person who provides it. It is important to maintain social contacts, concentrating on the pleasure of company and not worrying too much about the state the house is in or making mistakes.

Another possibility is to socialise with other carers and other patients. In Europe the Alzheimer cafés are spreading. These are places where sick people and carers meet and discuss in an informal ambience without having to worry about what other people think.

Taking Part in Help Groups

Alzheimer associations organise self-help groups for carers and some of them do the same for patients with this disease. Taking part in these groups offers an opportunity to encounter people who are experiencing or have experienced the same problems and allows them to free themselves of frustrations, exchange information and provide mutual support. The mere fact of going out and meeting other people can provide a little relief.

Accepting Help from Other People

Apart from moral help, friends, acquaintances and family relatives can be of help at a practical level as well. People should not be ashamed to ask for help. Indeed, help provided by other people can help those who provide care to a sick person to relax or enjoy a little free time, and this will help them to deal with the care they provide in a better way. The patients also benefit from the help of friends and family relatives who can support them and help them in continuing to do certain things for a longer period of time.

Addressing Feelings and Emotions

Managing Stress

A family relative can feel himself or herself subjected to great stress when he or she has to think about the future, organise assistance and face up to his or her fears. He or she feels wrecked physically and in terms of morale. The patients themselves can also feel destroyed when they try to understand a world that is becoming increasingly mysterious. For these reasons, it is important to create a support network and be vigilant as regards signs of stress. In this case one should address the problem immediately, engaging in physical activity, reducing the consumption of cigarettes, alcohol and coffee, and obtaining help. It is also important to have a good diet, have regular meals, avoid calorific snacks and sweetmeats, reduce the intake of salt, sugar and caffeine, drink a great deal of water and eat a lot of fruit and vegetables.

Managing Depression

There are many factors which can contribute to depression which, indeed, is not always understood. It is difficult to distinguish depression from pain, sadness or worry, given that it frequently happens that these sick people and the individuals who look after them feel in bad spirits, sad or discouraged in addressing so many losses and changes in their lives. However, in the case of depression the symptoms are more serious, they last for days or weeks and it appears to be impossible to attain a precise diagnosis and provide therapy.

Managing Fears and Worries

To care for a person suffering from dementia is a new experience for many people and it is accompanied by fears and worries. It is not rare for the carers to feel overwhelmed by what awaits them. The people with the disease also have fears and worries, the fear of being abandoned, of being a burden for other people, of 'going mad' and of losing control. The fear that dementia will become a mark is common and can lead a person to isolate himself or herself. Fortunately, things are changing thanks to greater knowledge about this malady but in certain cases the situation should be faced up to with courage. With the advance of dementia the patient may forget rules and etiquette and try to communicate as he or she can. It may be useful to explain to other people what dementia is.

Financial problems can also be a source of grave worries. Thus it is important to solve them as soon as possible and above all as long as the sick person is able to take part in the decisions that are taking. According to the case, the carer or sick person has the right to state help and to care, to tax exemptions or to financial help. People should be informed as soon as possible about the patient's rights and the help that is available.

Managing Rage

At time patients with dementia and the people who care for them are angry – with themselves, with each other, with the disease, with the frustrations of daily life, with medical doctors and with other health-care workers. Almost all of them encounter difficulties in managing rage. If managed correctly, rage can become constructive and can help in achieving positive change. But if it is repressed, expressed in an indirect way or in a disproportionate way as regards the trigger event, it can be destructive. Expressions of rage should not be confused with aggressive actions, but whatever the case it is important to manage rage in order to prevent and control aggressiveness. As a general rule, it should be observed that the best thing to do is to admit one's own rage and try to understand its causes.

Managing a Feeling of Guilt

The people who take care of patients with dementia often experience feelings of guilt. There are many reasons for this, amongst which we may list: past relationships with the patient, contrasting needs (work and family commitments), the consequences of the illness for their future, guilt at having triggered the malady, and an inability to take care of the sick person. If the carer has feelings of guilt he or she should not try to retrieve the past but, rather, he or she should concentrate on what should be done now and in the future, assure that the expectations are realistic and recognise his or her own limitations, and not feel guilty at accepting help.

Providing care can be wearing on the nerves. Accepting help from other people means having greater energy and continuing to look after the sick person for a longer period of time.

Addressing Changes in Roles and in Visions of One's own Identity

Each person has an idea of themselves, of who and what they are. The idea of oneself depends in part on the way in which people react and by the verbal and non-verbal signs that they send out.

Furthermore, everyone has different roles in life. For example a women can be a sister, a mother or a wife, engage in voluntary work, drive a car and be a teacher of chemistry. The roles that are performed contribute to the idea that a person has of their identity. Dementia makes it difficult and then impossible to perform certain roles. Those who take care of a sick person suddenly find themselves performing a role that they had not foreseen and for which they do not feel prepared. Perhaps they will find that other roles of theirs will change. For example, a wife will begin to feel that her role has changed, that from many points of view she now more resembles a mother. A person who has never attended to looking after the home may suddenly find that he or she has to cook, clean and do the shopping. These new roles require the acquisition of new skills but they also influence the person's sense of identity.

The Organisation of Help and Support in the Family Context

The best thing is not to see one person, automatically, as the principal carer but, rather, to discuss the problem with the family.

A family meeting is an advisable way to begin. People should ensure that all members take part, including the sick person if he or she is still able to do so. If it is thought that differences of opinion may arise, it is advisable to ask for help from a person outside the family.

People should be prepared for conflicts and differences of opinion, in relation to the 'best way' of organising care as well. It is advisable to be informed about the illness and its consequences so as to be able to give explanations to the others, where this is necessary. In addition, everybody should have an opportunity to express their own views.

An initial list of things that each person could do should be drawn up. One can decide to do this initially on one's own, knowing, however, that some people will provide help later on.

A note should be made of the offers of help because the others may forget about this. Members of the family who live far away can (by telephone or e-mail) also provide moral support, advice about financial problems, economic help or organise external services.

An attempt should be made to agree about concrete offers of help. A specific offer is useful; for example, offering to do the shopping every Tuesday or providing the patient with company every Thursday evening.

The children can also help. This also helps the children to accept the illness. For the children, the situation is different and is seen differently compared to the adults because they are still at a stage in life when other people take care of them and at times they encounter difficulties in accepting this inversion of roles.

There should be a periodic assessment of the form and scale of the care that is needed given that the advance of the illness changes the needs both of the patient and of the carers. Regular family meetings offer an opportunity to discuss the responsibilities, the problems and the feelings of each family member has.

A support plan that lays down the needs of the carers and how to meet them should be drawn up. This should be discussed at the family meeting and agreements should be made to speak about them subsequently with those who have to provide the services.

Financial and Administrative Problems

It is advisable for the patients and those who provide them with care to address these problems as soon as possible and to look for a solution. A carer can give direct help or look for external help.

It is advisable to discuss the problems with the person with dementia, draw up a power of attorney with a public notary if that person is still able to do so, make accounts separately, keep the receipts and note down expenditure. If a carer is not able to manage the finances of the patient, measures involving guardianship should be taken, the appointment of an administrator, etc.

Driving a Car

If the sick person has driven a car for the whole of his or her life, it is often the case that he or she will not accept not being able to no longer do so. Yet being able to drive is too dangerous for him or her and for other people. One can talk about this with the sick person, making him or her aware of all the risks, asking the medical doctor to explain the problem to him or her, accompanying him or her in the car and driving when this is possible, or using another form of transport.

Safety Problems

It is important to think about any problems that may arise and take precautions in order to reduce the consequences to a minimum. Problems of memory, concentration and attention provoke small errors (leaving the oven on or the water running, putting the shampoo in the refrigerator, forgetting about appointments, locking the door and forgetting to open the mail). Physical problems, such as deterioration in sight and hearing and defects in balance, can worsen the situation. Whatever the case it is advisable to strike a balance between the independence of the sick person, on the one hand, and safety, on the other.

A safe environment should be created and there should not be in reach objects and products that are potentially dangerous. Furniture and equipment should be steady and should not have sharp edges. The light should remain on during the night between the bedroom and the bathroom and electrical home appliances should be safe.

Habits should be changed: smoking and alcohol. The sick person should always have an address and telephone number in case of emergency and he or she should be warmly dressed when he or she goes out when the weather is cold.

A Healthy Diet

People suffering from dementia do not need special alimentation but they must have balanced and nutritional meals and they should drink a great deal: water and other drinks. It is advisable to create a pleasant and relaxing atmosphere during meal times, to be tolerant as regards good manners at table, and to use food preferences in a creative way by utilising sweet or fat ingredients in order to make the dishes more appetising.

Speaking, Listening and Understanding

The sick person will present difficulties in communication which with time will become increasingly serious. It is advisable to dedicate time on a regular basis to talking with him or her, establishing a visual contact and encouraging him or her, avoiding emphasising his or her mistakes, and not communicating messages that contrast with one another. Trying to interpret his or her 'body language', giving him or her a sense of security and support through physical contact, leaving notes to help his or her memory (with just one message), and using symbols, images and photographs to facilitate an understanding of the message that has been written down, should also be engaged in.

The Relationship with Children and Young People

Children can have a calming effect on a patient with dementia. Once they have understood what is involved, they manage to be affectionate and patient. Very many parents do not understand this and try to protect their children by pretending that nothing has changed. However the majority of children soon understand that there is something wrong and may think that they have done something wrong or be frightened at the strange behaviour of the sick person. It is advisable to explain to them what Alzheimer's disease is, to give them a sense of security and support, to encourage them to ask questions, and to give simple and sincere explanations.

A Lack of Interest in Hobbies and Personal Interests

The patient may remain seated without doing anything for a long time. It may also happen that he or she stops talking to other people and closes himself or herself up in himself or herself, perhaps as a consequence of his or her inability to communicate. However, with patience and perseverance it is possible to encourage the patient to do something and to become interested in what is happening around him or her. The patient should not be forced to do something that he or she does not want to do, he or she should be encouraged to engage in those activities that he or she is still able to perform, he or she should be congratulated when he or she manages to do something, he or she should be allowed to stop when he or she is tired, and his or her interest in things should be stimulated.

Disorientation

The person with dementia is often disorientated as regards time and space. This can derive from the confusion induced by cerebral degeneration, by memory loss or perhaps by difficulties in recognising things and people. The 'internal clock', which reminds us when we should eat or go to sleep, also tends to go wrong. The patient should be given a sense of security by explaining to him or her that there is nothing to get worried about. He or she should be helped to understand what time it is. Here it is useful to create a routine, to adapt the environment to his or her needs, to place objects always in the same place, and to place writing, drawings and labels on the doors and drawers.

Aggressiveness

The patient with dementia will often behave in an aggressive way, both verbally and physically (even though verbal aggressiveness is more common). It is always important to remember that the aggressiveness is due to the illness and not to the patient. It spares no one – even people with a very meek character can act in an aggressive way. One should maintain a calm and reassuring approach, try to distract the patient, avoid attitudes involving challenges or physical coercion, speak about what has happened and one's own feelings with a person who is trusted, inform the medical doctor, and try to discover the cause of the aggressiveness so as to stop it being repeated.

Physical and Recreational Activities

Whether one is dealing with recreational activities or routine domestic tasks, having something to do helps to organise the day, fosters socialisation, and helps in the measuring of the sick person's capacities. Many activities and pastimes are impeded or limited by memory loss and by problems connected with concentration or physical difficulties. It is, however, important to encourage the patient with dementia to have interests, to remain active and to engage in movement so as to keep his or her life as normal as possible. In particular, a sick person should be involved in daily activities, even though his or her help is not really necessary; activity should be suggested to him or her that can cause him or her pleasure; entertainment and not results should be emphasised; the activities involved should be simplified as much as possible; he or she should be made to engage in some activity in the open air; the length of activity should be limited to 15-20 minutes; the activity should be interrupted at the first sign of tiredness or frustration; he or she should be offered a glass of water or fruit juice at regular intervals; the task that he or she is able to perform should be identified and he or she should be provided with the help that is needed.

Many services exist to help people suffering from dementia and those who take care of them. However not all of these services are available in every region and every country. In addition, some of these services are financed by the state, whereas others have to be paid for. Fortunately, there are also a number of associations of volunteers who provide services for no charge. For this reason, it is advisable to address the local Alzheimer's association in order to obtain precise information. ■

FIFTH SESSION

NEURODEGENERATIVE ILLNESSES AND PLACES OF CARE: BETWEEN THE HOSPITAL AND THE LOCAL AREA

1. Pathways of Socio/Health-Care Assistance: Experiences in Italy and Europe

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Introduction

The subject of continuity in care and integrated care for patients with neurodegenerative pathologies constitutes an authentic challenge as regards the sustainability of state socio/health-care systems of a 'universalistic' kind, which, indeed, are typical of a welfare state which assures health care to all of its citizens. The aim of these state systems is to assure the protection of health as a fundamental right of the individual and a concern of society, respecting the dignity and the freedom of the human person.

Of the neurodegenerative pathologies, dementia is certainly the one that has the greatest socio/health-care impact. It has been calculated that in the world there are about 35.5 million people with dementia, with 7.7 million new cases every year and a new case of dementia diagnosed every four seconds. The number of people with dementia should triple over the next forty years. Most of these people will live in low- or medium-income countries. In Italy about 1,000,000 people have dementia and about three million people are directly or indirectly involved in helping loved ones who suffer from it.

The approach to patient care which is defined as 'disease management' has the aim of coordinating the resources of the whole of the socio/health-care system (and its actors) and assuring care of high quality during the whole of the continuum of the illness.

The National Level: the Drawing up of a National Dementia Plan

National dementia plans are important documents relating to socio/health-care policy because each State defines the actions of primary importance to be implemented in its various local areas in order to deal with the problem of dementia. Two forms of activity are by and large to be found in all the national dementia plans of the various Western countries: the identification of specialist centres for diagnosis and treatment ('memory clinics') and the implementation of socio/health-care pathways.

In the report of Alzheimer's Disease International of 2011 emphasis was placed on the need for specialist centres for the treatment of dementia, with a strategic reliance on the bringing together of highly specialist capacities rather than entrusting the management of the phenomenon to hierarchical capacities.

In Italy, in May 2000, at the time when cholinesterase inhibitors were put on the market, the Cronos Project was launched and this led to the identification by the regional governments of about 500 Alzheimer's Assessment Units (AAU). These bodies are multi-professional specialist centres which have the function of coordinating specialist medicine and general medicine in order to foster the integration of hospitals with their local areas. Thirteen years after the creation of these units in Italy, there remains, however, a need for a major reorganisation of such structures, which, indeed, came into being in very many regions without there being any authentic health-care planning. A census of 2006 of these units in Italy calculated that about 2,000 health-care workers – made up of specialist doctors (neurologists, geriatricians, psychiatrists), nurses, psychologists and rehabilitation workers – work in these units. Many have part-time contracts (this applies above all to psychologists and rehabilitation workers) with relevant consequences for the quality and continuity of the care that is provided to patients and their family relatives.

Italy was the first country to create specialist centres for the diagnosis of dementia. France, Germany, the United Kingdom, Austria and Ireland subsequently promoted the creation of 'memory clinics'. To summarise, these centres are the fulcrum of a socio/health-care system concerned with forms of dementia and around which has to be constructed a network of other socio/health-care services. Here we have in embryonic form the birth of a pathway.

The European ALCOVE Project, which involved the participation of fourteen member States of the European Union, revealed that a national dementia plan exists in many countries and is currently being approved in some. As regards Italy, there is underway a re-writing of the draft of the Dementia Plan which for two years was blocked at the State-Regions Conference while it awaited 'approval'. Meetings at the Ministry of Health with the reference points of the regional governments for the establishment of a new text to be approved only began again a few months ago.

It is curious to observe that from an epidemiological point of view only 50% of patients with dementia who are present in local areas in Western countries enter into contact with the socio/health-care services and are then diagnosed for dementia by specialist centres. In addition, this diagnosis is formulated during a moderate stage of the disease with a score of about 16 on the MMSE. The clinical paradox we can observe is that whereas, on the one hand, one can not swiftly identify all cases of dementia, on the other, there is a tendency to see – at times in too superficial a way – an individual with a cognitive deficit or even with a personal memory disturbance as a sick person. In this context, being able to make a distinction between those aspects of activity directed towards identifying pre-clinical stages of dementia (mild cognitive impairment), and the initiatives of state health care that seek to measure the clinical level of dementia, is of fundamental importance.

The Local Level: the Drawing up of a Pathway Made up of Diagnosis, Therapy and Care

National dementia plans envisage, amongst other actions, the implementation of pathways of diagnosis and processes of care.

Pathways made up of diagnosis, therapy and care are a macro-process that are in line with an overall management of a problem of health and they can be defined as multidisciplinary and inter-professional plans relating to a specific category of patients in a specific local context whose actuation is assessed through process and outcome indicators.

In the field of dementia the logic of a pathway of care is expressed as the need to integrate the activities of specialist centres that provide diagnosis and pharmacological and non-pharmacological treatment with the activities of general medicine, assisted health-car residences, integrated home care and relief admissions in order to make the whole system effective and efficient in the general handling of dementia. Evidence exists in the literature in the field that an organisation of these systems produces a delay in the institutionalisation of people with dementia, with consequent benefits for individuals and society as a whole. Integrating health-care systems with social systems by creating a shared cultural paradigm, and going beyond the bureaucratic and sterile distinction between the two systems, is of urgent importance: the real world of patients and their family relatives dramatically requires a cohesive response on the part of institutions.

To summarise: to achieve a good pathway of care, the following are indispensable: a) a multidisciplinary and inter-professional approach; b) recommendations based upon scientific evidence; c) the local adaptation and sharing of the plan; d) a pathway sub-divided into stages of specified duration; e) a clear idea of who should do what and when during the various stages; f) an assessment with process and outcome indicators; g) the involvement of the patients (and the caregivers).

In addition, a good pathway of care should only do that which is useful (theoretical efficacy), in the best way possible (practical efficacy), with the lowest costs possible (efficiency), for those people (accessibility) and only those people who really need it (appropriateness), with care being provided only by those who are qualified to do so (competence), obtaining the results that are held to be the best (satisfaction).

Experiences in Italy and the Rest of the World

In Italy, experiences in the field of pathways of diagnosis, treatment and care in the field of dementia are known about (Milan and Brescia). The pathway practised in Brescia, which was begun in September 2011, without doubt has made the most innovative contribution. The socio/health-care pathway is sub-divided into the following stages: the stage of a suspected positive diagnosis, the first diagnostic assessment and the beginning of the specialist stage (with a preferential pathway that assures a limiting of the waiting time for the first examination at a centre for dementia); a diagnosis and the possible beginning of treatment; management of the follow-up with preferential pathways in order to assure the limiting of waiting times for access to centres for dementia; the monitoring and home management of the patient (report of the general practitioner/specialist of the centre for dementia, the unit for multidimensional care continuity of the ASL and home services); the management of entering day and residential services of the local-area network; the management of psycho-behavioural disturbances: information, training and support for the family relatives and caregivers in order to achieve a correct management of the patient; and the training of the health-care workers in order to achieve qualified care provision.

The role that the centres for dementia can play in the overall process of diagnosis, treatment and care involving the patient takes place in two stages: a first stage where the principal objectives are the diagnosis and a possible beginning of treatment, and a second stage which takes place after the diagnosis whose principal objective is the monitoring of the patient through periodic repeated assessment in order to detect possible existing (somatic, cognitive-behavioural, social, care-related) problems and to draw up strategies for solving them.

Conclusions

To conclude: the implementation of socio/health-care and care pathways are a concrete translation of the 'policy of doing' in facing up to the dramatic problem of dementia in various areas. There is an urgent need to transfer the best scientific evidence available to clinical practice in order to improve the quality of care and overcome inequalities through the establishment of national standards. Such pathways should not be shut up in the drawers of desks without them ever interacting with actual realities.

During a time of profound crisis for Western societies one must have the courage and the capacity to invest human and financial resources so as to achieve an improvement in socio/health-care systems, aware that the results will be visible at the level of populations not in the immediate future but in the medium and long term. There is an urgent need for an integration of these systems with the world of voluntary work and the third sector in order to promote information, training and the spread of good practices. We have to combat the stigma that accompanies dementia. Dementia is a real challenge for the social fabric and it is a pathology that is associated with deep loneliness.

In addition there is an urgent need to promote a global approach to dementia by trying to avoid an opposition between rich countries and poor countries, between hyper-technological medicine (PET, SPECT) and basic medicine, with a search for simple and inexpensive instruments by which to carry out diagnoses and engage in treatment to which everyone has easy access.

One cannot expect a 'miraculous pill' if we keep our hands in our pockets. We have to leave behind us a medico-centric and medical product-centric vision of dementia. Complex pathologies require answers of the same level through an organisation of services. The political world has a responsibility to promote strategies that involve the primary and secondary prevention of dementia. A great deal of available evidence has identified seven risk factors – which potentially are modifiable – associated with the appearance of dementia caused by Alzheimer's disease: diabetes, hypertension in adulthood, obesity in adulthood, smoking, depression, low levels of schooling and physical inactivity. It is estimated that about a half of the cases of dementia caused by Alzheimer's disease can potentially be attributed to these factors as an overall category. The level of the schooling of the new generations should be increased, social integration and cohesion should be fostered, and the loneliness of elderly people should be combated. In this way, over the next thirty to forty years, we will have fewer cases of dementia. ■

2. ROUND TABLE
BEST PRACTICES: SIMILARITIES AND DIFFERENCES IN CERTAIN NATIONS

2.1 Australian Aged Care Facilities Understanding Dementia: a Necessary Precondition for Best Practice Care

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As has been addressed elsewhere during this conference, dementia (which is the neurodegenerative illness that is the focus of my talk) is a progressive, incurable syndrome that affects primarily older adults. It is estimated to be caused by over 100 conditions, with Alzheimer's disease accounting for approximately 70% of all cases. It leads to global destruction of brain tissue, and ultimately affects all aspects of the affected person's life up to and including their death. We yesterday heard from Professor Finlay in respect of palliative care, and I and many Australian colleagues advocate a palliative approach for people with dementia – this is a life-affirming approach to care that anticipates and responds to needs across the dementia trajectory.

A holistic approach to care acknowledges the physical, psychological, social, emotional and spiritual in understanding the fullness of human existence; in nursing especially, but also in other health disciplines, this holistic philosophy has assumed rhetorical prominence over the last three decades. The rise of scientific medicine with its emphasis on the pathological over the last 150 years has seen the physical and psychological domains in respect of health dominate; while the holistic philosophy does not seek to negate these domains it argues that the social, emotional and spiritual are of equal value in the hierarchy of health effects, and that to dismiss these is to fail to respond to the personhood of the individual we come to meet in care.

As a general rule it is physiological discourse that dominates in our understandings of what illness means, and those of a holistic persuasion usually struggle to engage health carers in broadening their gaze to recognize and respond to the wholeness of the human and their lived experience. The second most prevalent focus in health care is generally the psychological (which in many respects has modeled itself on the medical model and its basis in pathology). Indeed in dementia, much emphasis has understandably been placed on the behavioural and psychological symptoms of dementia (BPSD), owing both to their prominence in the early and moderate stages of the condition and their disruptive influence and contribution to the suffering of affected individuals and their carers. In fact, my own work and that of my colleagues in other Australian States demonstrates that it is the psychological, particularly the psychopathological lens that dementia is primarily constructed through, and in our experience this way of conceptualizing and understanding dementia is problematic in a number of ways that I will speak to you about shortly.

My brief contribution to this round table will address best practice and associated challenges for people living with dementia, their families and carers in a particular place of care, that being Australian aged care facilities (known elsewhere in the world as nursing homes). I take this focus in large part because my work has been situated in this context for the last decade as the result of research appointments locating me within the residential aged care sector. Some of the learnings gleaned from this environment have potential applications elsewhere, but they remain to be tested in community dwelling or acute care contexts, underdeveloped areas I am hoping to connect with in future projects.

Currently in Australia, which has a population of 23 million, there are approximately 300,000 people with a dementia diagnosis – owing to the difficulty in obtaining such a diagnosis this figure is likely to be an underestimate. Projections indicate that this number, like that observed in most nations around the world, is increasing rapidly, and is likely to treble to an estimated 900,000 over the next three decades. The Australian Government in its *Living Longer, Living Better* package has recently responded to these figures – as well as ageing demographics more generally – by creating a program designed to encourage people to be supported at home until late in their illness course, at which time those who wish to will be supported to move into residential care. It is estimated that currently approximately half of those with moderate to advanced dementia in Australia are resident in aged care. In my country nursing homes are divided into two levels – high care and low care. In high care, which provides for the most dependent and frail older adults, it is estimated that 80% of residents have dementia as a primary diagnosis, while in low care the figure approaches 60%, and both of these figures are on the rise. It is postulated that over the next decade low care will cease to exist in its current form and aged care institutions will be almost totally populated by those experiencing advanced dementia. For these individuals in particular it is imperative that their carers have a broad understanding of the pathology of dementia and crucially its life-limiting nature if goals of care and associated practices are to be appropriate and promoting of the individual's quality of life.

Ironically in dementia care, and in contrast to its dominance in most other illnesses, less focus is placed on the more global physiological effects of dementia on the person, particularly as it progresses to the advanced stage and the individual approaches the end of their life. Dementia is a progressive illness; the person's symptoms and associated needs change across its trajectory; failure to understand its underlying physiology and course can result in inappropriate and unhelpful interventions. This is not to say that the persons themselves are understood through the lens of their physiology, but that to fail to acknowledge the physiological impacts of dementia is to make full understanding of the affected person and their care needs extremely difficult.

To see the person through the lens of their disease alone is to risk losing our sense of them as a person; the loss of recognition and valuing that besets the person with dementia owing to the Cartesian understanding that cognition equates with personhood has been rightly and powerfully critiqued by Thomas Kitwood and others. However, to some degree the pendulum has swung so far that to even describe dementia as a progressive and irreversible loss of cerebral function is to incur the wrath of the many who see this as inevitably diminishing of the person with the condition. On the contrary, however, I argue that to see the person as somehow distinct from or unaffected by the condition that is affecting them is equally to risk missing opportunities to respond to their care needs. I absolutely assert that one can conceptualize the disease that is dementia leading to loss of cognitive function without seeing it as leading to loss of the person. The challenge posed in caring for those with dementia is to balance our understanding of the pathophysiology of the conditions that cause it with our complete and abiding valuing of and respect for human dignity throughout the illness course. It is only by so doing I would argue that we can fully respond to the person in their physical, psychological, social, emotional, spiritual self – and recognize, too, that the human person far exceeds the sum of those 'holistic' parts.

So, what are some of the risks posed by not understanding dementia pathology and the dementia trajectory? Let me provide a couple of quite distinct examples. I commenced work as a researcher with an aged care organization, and spent some time observing and discussing their care practices for people with dementia. I was told of a recent project the facility had trialed called a 'domestic model' of care. Among other activities, a key plank of the model involved affected individuals being assisted by their facility carers to participate in making their breakfast each morning: buttering toast, making tea and so on; the sorts of activities most of us engage in as one of the bookends of our waking day. The project went happily for several weeks; apart from the enjoyment of the morning activity, improvements in sleeping, anxiety, engagement, and other behaviours were noted. And then, seemingly inexplicably, the enthusiasm started to taper, and over the course of another few weeks the breakfast activities reverted to the care staff resuming their role of providing for the residents who sat as passive recipients. Feedback from the staff included that 'it didn't work', 'was a waste of time', and 'too difficult'. When interrogated further, it transpired that care staff had assumed that the residents would 'learn' to make their own breakfasts; that they continued to require prompting and other forms of assistance meant that the model indeed 'hadn't worked' – indeed it was an abject failure.

The staff in the above instance were operating from particular understandings of dementia and subsequent goals of care that did not equate with either the activities undertaken or the needs being addressed. They were functioning from within a rehabilitative, indeed restorative model and associated understandings. In the absence of knowledge of the nature of dementia at the physiological level, these staff saw their purpose as 'teaching' residents to regain previous executive, instrumental and other levels of functioning. While indeed some function can be maintained or temporarily regained via approaches such as the domestic activity approach or through the progressively popular Montessori method, such gains, while meaningful, important and worthy of celebration, are not going to restore the person to their pre-morbid state. Rather, we connect with the affected person in meaningful ways that enhance their quality of life, but in the full understanding that these engagements have value in and of themselves but are not designed in any way as curative. A lack of understanding of the pathophysiology underpinning the dementias is crucial if we are to set realistic, achievable and sustainable goals of care.

My second example relates to a particular part of the dementia trajectory experienced by people with dementia as they move from the moderate to advanced and final stage of their illness. As the neurodegeneration progresses the individual, who may have earlier exhibited classic dementia-related behaviours such as repetitive wandering, pacing, vocalizing, perseveration and so on, or acted in aggressive or otherwise inappropriate ways, starts to exhibit these less as their capacity to do so wanes. This usually coincides with a diminishing capacity to mobilize and is crucially frequently a reflection of disease progression. Concerningly, our recent research identified that far from reflecting deterioration, both family members and care staff saw such changes in behaviour as an improvement in the person's condition; family spoke of their loved ones as 'turning a corner', 'getting better' and 'getting over' their dementia. Staff and family also both spoke of dementia as 'a mental condition' or a condition 'of the mind', and importantly did not perceive it either as a condition of the brain or as having more global physiological impacts. At the time that the person with dementia starts to experience reduced ability to mobilize, they also classically experience associated complications and not uncommonly present with repeated episodes of aspiration pneumonia and other immobility-related infections and conditions. In the absence of an understanding of the physiology of dementia and its trajectory, affected individuals can at this point be responded to as though they were in fact physically well, and subjected to burdensome, invasive and futile care that can contribute to their suffering as well as potentially accelerate their cognitive decline through such phenomena as delirium being exacerbated by hospital transfer. Failing to understand the dementia trajectory and its terminal nature can lead to enhanced suffering of all involved, but particularly of the person with dementia who relies on us to provide evidence-based, supportive care.

In response to the above challenges, my and my colleagues' work is focused around providing families and care staff of people with dementia with accessible and accurate information about the condition. Traditionally, staff training around responding to BPSD for example takes a somewhat formulaic approach – for example some might promote Montessori, others reminiscence therapy, still others music, doll or pet therapy or combinations thereof. While care staff in Australian aged care are overwhelmingly motivated and engaged, in our professionally deregulated environment they have little formal and often less professional education – for a group that provides almost three quarters of the hands-on care for a progressively vulnerable and impaired resident population this issue cannot be underestimated. Whatever the behavioural approach taken and however 'person-centered' it may be, it must also be underpinned by an understanding of the nature of dementia and what is happening physiologically to the affected person. In the absence of this it is I would argue impossible to provide mindful and responsive care. In respect of dementia as a terminal condition, our work has shown that educating families about the dementia trajectory contributed to their being able to connect with their loved one in an enhanced way, with far less anxiety about what to expect from day to day and what particular changes might mean. Families expressed relief and gratitude for their improved understandings. Staff likewise responded in a positive fashion and experienced less frustration in care provision that was geared to positive, achievable goals.

Far from being a hopeless situation – yes, dementia is progressive, incurable and fatal – if provided in a sensitive manner such knowledge provides carers and families with hope of making a real difference in the life of the person with dementia, albeit in the recognition that their life is limited by this most cruel condition. If on the other hand we operate in ignorance of dementia pathology then we close off opportunities to understand and respond to the person's needs in an informed way that maximizes both the quality of their living and their dying. I and my Australian colleagues argue that best practice is that which is underpinned by knowledge; certainly knowledge of the approaches taken and their indications, but critically also knowledge of the condition that is dementia. We have recently embarked on an 'Understanding Dementia' Massive Open Online-access Course (MOOC) and have been overwhelmed by the sustained international response from almost 10,000 people with dementia, their families and a wide range of health professionals – it confirms our belief that it is only by understanding this condition that the full personhood of affected individuals can be embraced and holistic, best practice care attained. ■

2.2 An Overall Approach to Care for Elderly People with Neurodegenerative Diseases in Chile

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During the course of the twentieth century, amongst many other political, social and cultural changes, important demographic changes also took place which in most industrialised nations are a reality but which in many developing countries remain a trend.

These changes were caused by scientific development and by its technological impact but in part they were also the outcome of policies directed by populist and economics-based ideologies whose rational and ethical foundation was neither clear nor pertinent, for example the ideologies of 'family planning' and 'birth control'.

In both cases the evident effect has been a change in the traditional demographic profile which at the present time is characterised by a sort of inversion of the demographic pyramid or rather by a geometrical metamorphosis, given that its current form resembles a rhomboid shape.

The result of this 'demographic inversion' has been a net increase in life expectancy which prolongs life spans and the number of adults who reach an advanced age, and to such an extent that the presence in all societies of people in their eighties, in their nineties and even people who have gone beyond the psychological barrier of a century is no longer strange.

Obviously enough, however, this greater longevity of people has led to an increase in social, cultural and biomedical situations which were previously practically anecdotal. Amongst these situations we may refer, as regards the health-care field, to a greater prevalence of those diseases of a chronic, progressive, invalidating and irreversible character which afflict the working of the central nervous system and which are called collectively 'neurodegenerative diseases'.

This set of diseases generated by pathological processes of a degenerative nature, which are often associated, though not exclusively, with elderly people, refers essentially to various levels of alteration and loss of our higher intellective functions, from light cognitive deterioration to grave and invalidating dementias of any aetiology, even though we know that the predominant forms are Alzheimer's disease, various kinds of vascular dementia, and Parkinson's disease.

The enormous problems associated with these pathologies are not only a grave deterioration in performing basic functions and the performing of the activities of daily life of elderly people who have them, but also, and with a great familial, economic and social impact, the complex situation produced within families and society as a whole by the need to provide for many years care of various kinds of complexity and cost to these patients, within the context of a shortage of infrastructures and financial resources and of technical and psychological training to address problems that require some people to be absolutely responsible for the care of other people, which in turn requires, in addition to resources, also charity.

In this context, each nation has provided various alternative supports, according to the resources that are available and the level of understanding of these diseases and concern about them. In some cases one is dealing with contingent and partial solutions and in other cases with real long-term government policies which thus include various measures, some of which are purely of a care and hospital character to address acute clinical situations, and others that take into consideration the entire gamut of basic and intermediate forms of care and treatment for elderly people who have neurodegenerative diseases, which are provided on a gamut that goes from hospitals to homes.

From a demographic point of view, Chile is experiencing a reality similar to that of the more developed nations but one which is still far from being addressed with a political approach of a long-term character and with resources that are sufficient and necessary to obtain an impact that really improves the quality of life of elderly people with neurodegenerative diseases, their families and health-care workers.

My paper will briefly describe the epidemiological situation as regards ageing and neurodegenerative diseases, outline the structure of the health-care system in Chile, describe the principal public and private initiatives in this field, and, lastly, offer some brief observations on the most common problems and what the future is likely to bring.

1. Epidemiology

The demographic profile of Chile resembles a rhombus, like that of many other countries, with an increasingly narrow base because of a drastic reduction in the birth rate caused by cultural changes and government policies that were introduced in the 1960s. The apex is expanded because of the increase in the elderly part of the population, starting with greater life expectancy, principally caused by a reduction in illness and death rates brought about by the use of antibiotics, better diagnostic and therapeutic technologies, and a greater promotion of health and the prevention of illnesses, in particular perinatal and childhood ones.

At the present time, in a population estimated by the National Institute of Statistics in 2013 as being made up of 17,556,815 inhabitants,[1] almost 15% are over sixty, that is to say two and a half million people in all.

The present old age rate is 67.1 and it is estimated that by 2025 it will have reached 100. 56% are women, 61% are heads of families, 58% are married and 24% widows/widowers, and 61% are digital illiterates, that is to say they cannot engage in any activity on Internet.[2]

Neurodegenerative diseases afflict between 5% and 8% of people over the age of sixty-five, between 15% and 20% of people over the age of seventy-five, and between 25% and 50% of people over the age of eighty-five.[3]

Alzheimer's disease is the most frequent form of dementia and makes up 50% to 70% of the total of dementias, with a higher percentage rate in patients belonging to groups of advanced age. Vascular dementia comes second.

2. The Structure of the Health-Care System

With an average of 559 inhabitants per medical doctor, the health-care system in Chile is divided between a public sector and a private sector. The public sector is organised around levels of increasing complexity.

The level of primary care is made up of institutions of health care of a clinical character with less complex services that are managed by professionals and technicians who in the medical field are general practitioners or have basic specialisations. This sector, which has on average 20% to 30% of the total of hours of health-care services, serves 60% to 70% of the spontaneous demand for health-care services. It is a sector that is technically under the Ministry of Health and local authorities, and this is the result of a process involving the transfer of administrative management from the central level to the local authorities that took place in 1988.

The secondary and tertiary levels are made up of health-care institutions of a hospital character which are more complex in their services and include basic and derived specialisations. This sector serves 20% to 30% of spontaneous and derived requests and depends technically and administratively on the Ministry of Health.

Overall, the public sector makes up 44% of the total hours of health-care services in the country and serves 80% to 90% of the demand.[4] The number of inhabitants per medical doctor in this sector is 920, almost double the public and private national average. Those who provide care in geriatrics are usually medical doctors who have developed their own training in this area or who have received training abroad: there are about sixty in the country. In 2012 the Chilean government decided that geriatrics is a derived specialisation, that is to say that it requires a preliminary study of basic specialisation in basic medicine lasting three years, and thus the training of a doctor in geriatrics in Chile requires a total of five years of study.

As a consequence, even though within the political discourse of various governments a certain level of concern about the ageing of the population and illnesses connected with this process, amongst which we may list neurodegenerative diseases, is present, the truth is that true progress in the development of all the biomedical, social, cultural, economic and functional aspects in favour of a more balanced quality of life for elderly people has been marginal.

The private sector, which complements the public sector, includes both open and closed institutions, usually as part of integrated vertical holdings of the same clinical institutions and companies for the management of private health insurance which are known collectively as 'Isapres'. These were created in the 1980s when the principle of solidarity was replaced by the principle of the subsidiarity of state in the field of health insurance.

This sector has between 60% and 70% of the hours of health-care provision, those in it are paid two to three times better, and serves only 20% to 30% of the demand for care at all levels of complexity. In this sector, the number of inhabitants for each medical doctor is 276, a figure similar to that of industrialised nations.[5]

The ratio of inhabitants per medical doctor between the public and private sectors is 3.34. Even though in the private sector the conditions of care are very similar to the standards of developed nations, with very high costs, in this sector as well geriatrics is not fully developed as a specialisation, for the same reasons as above: a low critical mass of specialists, many of whom developed their own training, without support networks in the form of infrastructures, supplies, medical services or other health-care workers needed for an optimal working of the system

3. Private Initiatives

As regards private initiatives for elderly people in general, and those who have neurodegenerative diseases in particular, in the scientific and academic fields there stands out the Chilean Society of Geriatrics and Gerontology which brings together professionals from various fields of clinical and epidemiological research in the sphere of prevalent neurodegenerative diseases and other pathologies which are seen to be typical of elderly people.

In terms of infrastructures and equipment for care and treatment of elderly people in general, there are private old people's and nursing homes – a lucrative market which offers marginal benefits to its users.

Here we are dealing with special homes or private habitations suited to having old people which have rooms with a number of beds, although also at times single rooms, with bathrooms and meals in common, with an average of ten elderly people for each assistant, with assistants or technicians with little or none of the specific training that is required for elderly people in general, and obviously much less trained for caring for those patients who have irreversible invalidating diseases, such as the dementias which I discussed above, which are the most important as regards known neurodegenerative diseases as a category.

These homes usually have people pay a monthly rent which oscillates between 1,000 and 1,500 American dollars.[6] Usually there are general medical doctors who provide weekly or monthly care, or care on request. Geriatric care does not exist. Not even by specialists who have a familiarity with the processes of neurological deterioration of a degenerative kind.

The minimum wage in Chile is about 420 American dollars and the average family income is about 1,250 dollars a month.[7] That is to say, a family with a single average income and an elderly member disabled by illness, above all if neurodegenerative and requiring constant attention, has to choose between care for the family member at home or in an institution, with a grave reduction in this case of the family budget, which is almost incompatible with survival.

Some religious institutions, such as the '*Hogar de Cristo*', a work founded by the Jesuit St. Alberto Hurtado in the 1940s, the homes of Dominican sisters, or the Hospital Order of St. John of God, have dedicated years of charitable effort by their religious or lay members to supporting families and projects to help the elderly, in particular those that live on the streets, abandoned by their families, without their own resources, without support from the state, and often addicted to alcohol and drugs. These elderly people are accommodated in homes dependent on the public charity of their members. Obviously, they do not have specialised geriatric care and even less care relating to neurodegenerative diseases.

4. Public initiatives

In the public sector, initiatives for elderly people are planned and implemented through the National Service for Elderly People (SENAMA), a body that forms a part of the Ministry for Social Development. However, these are projects that concentrate on social and recreational activity with a minimal emphasis on the geriatric aspects, that is to say the clinical aspects, of ageing, and even less on the curative needs of neurodegenerative diseases.

There are also permanent initiatives such as the Health Programme for Elderly People and the Preventive Medical Examination for Elderly People which were created by the Ministry of Health and installed about ten years ago in institutions for primary care, but without equal representation at the level of hospitals where acute geriatric units are usually reduced to a couple of beds in the service of internal medicine.

The only public institutions that possess physical and human resources that are specialised in geriatrics, including neurodegenerative diseases, are the National Institute of Geriatrics, the 'Irene Morales' Geriatric Centre and the Geriatric Service of the Military Air Force Hospital, all of which are located in the city of Santiago.

As can be easily understood, if there is not an adequate and sustained development of geriatrics as a clinical specialisation, it is less probable that an adequate development can exist of those organisational and working structures that are needed to address a part, furthermore a large part, of the problems that this specialisation deals with.

However, to tell the truth, it is also necessary to note that the SENAMA provides certain programmes to support quality of life and activities performed by elderly people, such as programmes of social tourism, the National Fund for the Elderly, consultants for the elderly, training schools for directors of organisations for the elderly, schools for civil servants, programmes against paedophilia and the ill-treatment of elderly people, long-term accommodation (ELEAM) and protected apartment blocks.

The last two are intended to provide basic and intermediate help to elderly people who are partially or totally not self-sufficient, including those who have neurodegenerative diseases.

ELEAM in particular seeks *to provide accommodation for vulnerable, dependent and without support elderly people* and helps 142 people in ten centres in Chile.

The aim of the programme for protected apartment blocks is *to provide accommodation for elderly people who are in situations of vulnerability, are self-assessing and without support, with the addition of psycho-social support for the beneficiaries*. It helps 798 people, none of whom have neurodegenerative diseases.

The School for Civil Servants is an interesting initiative in the field of local care for elderly people who have neurodegenerative diseases and its goal is *the training in social gerontology and specialist care for elderly people of those people who work in local networks for elderly people and those people who provide service in the ELEAM*. This school has 272 members.

In the year 2010 elderly people with neurodegenerative diseases in Chile numbered 229,835, that is to say about 10% of all elderly people. Of these, the public system directly supported through ELEAM 0.06%.

Overall, 233,993 elderly people benefit from these programmes, of whom 71% are women, according to the data provided by SENAMA. This is about 9% of the elderly part of the population of the country.

5. Frequent Problems

So what is the real situation of care for elderly people made invalids by neurodegenerative diseases in Chile? What are their real and daily problems?

The statistics demonstrate in numerical terms a qualitative reality of abandonment by the family with the loss of both social networks of support – that of work and that of friends. But they also reflect a reality of material poverty, highlighted by the small income received by pensioners which on average is 400 American dollars a month.[8] Principally they reflect a poverty of spirit highlighted by an abandonment by families of their elderly people in general, and in particular of those who because of their state of health have become a burden, a burden which contemporary generations, who are gripped by utilitarianism, hedonism and consumerism, do not want to shoulder.

This situation of abandonment and poverty, together with limited human and material resources, whether public or private, produced and directed towards care for elderly people, above all those with dementia, makes the national situation in this sector more than precarious, if not worse than precarious, given that the best care practices cannot be implemented without sufficient resources.

Functioning well in the activities of daily life, starting with basic activities and moving upwards, are a part of the reality of these people who, in their state of dependency, do not have appropriate forms of care and treatment, at the level of quantity, quality and costs, both in the public sector and in the private sector.

Families have to take responsibility for care and treatment, without any training, without economic resources or institutional support, and often unwillingly.

Those who provide accompanying, in addition, constitute what is not a lesser problem. The 'caregiver syndrome' is well known: authentic burn-out in those who provide this care, above all when they are alone and not trained.

6. The Future

Lastly, what about the future? The panorama that has been outlined, even though it is sad, should be a source of energy in our becoming aware of this reality.

Some of the recommendations to be made, according to the nature of government policies but above all because of personal conscience, are: *instruction*, both as regards academic and clinical resources and people themselves, that is to say elderly people and their families who must be trained to face up and deal with future disabilities, and of those who must perform a compassionate and supportive role and take care of them. To be produced, these resources at the level of training require public and private requests.

There should equally be an *urban planning and architectural vision* so as to overcome the barriers that limit the activities of elderly people in order to provide safe and comfortable accommodation, offer true parity of access, with adequate coverage for those who need those special forms of care that are required in the case of neurodegenerative diseases.

Another relevant change should be that of the *social roles* of elderly people, both to prolong their normal working activity, where this is possible, and to redirect their social contribution in terms of the transmission of the knowledge and the experience that they have acquired which can be shared with the young generations.

Lastly, *the prevention of illnesses and the associated promotion of health* in all its forms must constitute from a purely biomedical point of view a permanent task of the world of care and the academic world.

But in reality the most important and significant change that can really improve the lives of elderly people is a change in personal attitudes towards them.

Notes

[1] National Institute of Statistics (INE). http://www.ine.cl. Date of access: 03/10/2013.

[2] Ministry for Social development. National Service for the Elderly (SENAMA). *Report on National Management 2012*. http://www.senama.gob,cl. Date of access: 03/10/2013.

[3] Ministry of Health. Department of Epidemiology. http://epi.minsal.cl. Date of access: 25/09/2013.

[4] Ministry of Health, Under-Secretariat of Care Networks, (2010). *Study of Supply and Demand of Specialists doctors in Chile, in Cuadernos de Redes*, n. 31.

[5] *Ibidem*.

[6] Information requested in each 'residence', often personally. A 'directory' of these places or something similar does not exist which centralises and facilitates the gathering of information (author's note).

[7] Estimate.

[8] Estimated average. In general it is lower (author's note).

2.3 Germany

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Let me begin by giving you an overview of the situation of neurodegenerative diseases in Germany today. Currently, more than 1.4 million people in Germany suffer from a form of dementia. This figure is set to double by the year 2050, while at the same time the total population is expected to decrease substantially. This means that by the year 2050 approximately 4% of the population of Germany will suffer from some form of dementia. Each year around 250,000 new cases of dementia are diagnosed. Two thirds of those affected by dementia suffer from Alzheimer's disease.

Due to demographic developments, the prevalence of Alzheimer's is increasing in western industrialised countries. While around two per cent of 65 year olds in Germany are affected, this prevalence rate increases significantly among older people, with around 25% of 85 year olds showing symptoms of the disease. There are currently around 4 million people in Germany over the age of 80. This number is set to rise to 10 million by the year 2050.

Dementia is a chronic, progressive disease whose sufferers have exceptionally long-term and intensive care needs. The average life expectancy from the time when the first symptoms appear to the date of death is around seven to nine years. According to a German Federal Government report on the elderly, the annual treatment and care costs for people suffering from Alzheimer's are already estimated at around 26 billion euros.

Of the 1.4 million people affected by Alzheimer's in Germany, around 400,000 live in residential care facilities for the elderly. However, the significant majority lives at home with relatives or in-house carers, or live alone. The number of elderly people living on their own is increasing. This is an important factor to note as it indicates the approach of a massive problem: due to demographic changes, we must assume that in the near future social structures which have been built around the family will disappear.

We therefore urgently need to address the question of how to close this colossal gap in the provision of care for people suffering from dementia. The shaming fact is that we have not yet succeeded in developing a comprehensive and sustainable social concept for promoting intergenerational relations. In my opinion, our society has fallen short on two main counts; with respect to carers and in the provision of funding.

Our future in old age will depend decisively upon whether sufficient numbers of young people can be attracted to professions which will fulfil the medical, therapeutic and caring requirements of health-care provisions in the years ahead. And financially it is foreseeable that provisions by the state will not suffice. Therefore, in a society of longevity, every individual must also invest more at a much earlier stage in their own preventative health-care measures, and in the provision of high quality medical and long-term care.

Today we already have a social divide: well-off families in need of care for family members in Western Europe often resort to the so-called 'Polish' solution. This refers to the engagement of (mainly) women from outside Germany – often well-trained carers from countries such as Poland or Romania who provide round-the-clock in-house care. Nowadays it is possible to find qualified foreign carers who will look after our elderly for between 1,000 and 1,500 euro per month. However, these women often leave behind families, who must go without a mother or daughter for months at a time, and deprive their home countries of skilled workers. This legal form of employment is a modern form of exploitation and not worthy of one of the richest countries in the world!

Unfortunately, sustainable political concepts for addressing these immense financial and personnel requirements on our own are lacking. This requires commitment on the part of politicians and society as a whole. It requires long-term solutions which cannot be conceived in terms of single legislative periods. However, faced with so many problems resulting from increased longevity, politicians in Europe appear to have lost the will to tackle intergenerational issues.

There is no treatment for the causes of dementia. Therefore what other possibilities are there for providing care? Those suffering from dementia experience the progressive loss of everyday skills and personality traits, leading to a need for assistance in many areas. The aim should therefore be to delay the progression of the disease and improve support for patients and relatives.

The main goals in the provision of medical care for older people are to preserve their independence and promote self-reliance, to avoid the need for care services, and to enable them to remain in their homes for as long as possible so that they may maintain their quality of life for as long as their health permits. Crucial to achieving this is the role of the family physician in early diagnosis. With the subtle development and slow advance of the disease over many years, accompanied by progressive cognitive and physical impairment, the family physician who has been caring for a patient for a long time is usually the first to identify the typical symptoms of dementia caused by Alzheimer's.

Family physicians also play a

decisive role in the provision of care. Through cooperation with relatives, carers and members of other health-care professions, a variety of measures can be implemented at different levels to support patients and their families in their homes. This can include, for example: memory exercises and training in everyday tasks, as well as physiotherapy and occupational therapy for patients; patients may be assisted in their homes though the assessment of interior arrangements and the identification and removal of stumbling hazards, as well as the provision of medical aids and the maintenance of familiar surroundings; assistance may also be provided on an everyday basis, for example though home help, care services, or 'meals on wheels' schemes; it is important to maintain social contacts. Self-help groups exist for both sufferers and their carers, as well as therapy groups. Advice and support for relatives, who often have difficulty coping, is highly important; and finally, consideration should be given to important legal aspects, such as drawing up a living will, granting power of attorney and appointing a legal guardian.

Let us now consider the situation with regard to social security. What rights do patients have? The aim of rehabilitation is to avoid the need for long-term care. Studies show that geriatric rehabilitation also proves effective for patients suffering from dementia in reducing dependence upon care and in avoiding or delaying the necessity for transferral to a care home facility. This is of great significance, not only in terms of the quality of life for the patient, but also financially. Rehabilitation measures should always be undertaken before resorting to long-term care, therefore there is an urgent need to extend the provision of local outpatient and inpatient geriatric rehabilitation centres. Such rehabilitation centres do exist, however there are currently far too few of them. In addition to this there are day centres and care homes which provide short and long-term care. Day centres provide care during the day for patients who live at home. Short-term care offers the possibility for patients to spend a limited amount of time living in a care home, for example in order to provide a period of respite for relatives who care for them. Patients in long-term care live in care homes which provide complete, round-the-clock care. How is this financed?

The Act on Long-term Care Insurance (Eleventh Book of Social Code) which was introduced in 1995 sets out the legal definition of those in need of care and defines the pre-requisites for the provision of monetary benefits or benefits in kind. This sets out three 'care levels', which are defined according to the perceived degree of need. Until recently, long-term care requirements under this insurance scheme were mainly assessed according to physical needs – these are different levels of assistance pertaining to personal hygiene, nutrition and mobility. People with dementia were routinely disadvantaged.

Changes introduced to care services under the Care Adjustment Act of January 2013 are set to benefit more than 650,000 dementia sufferers this year. This new law was intended, in particular, to relieve the burden upon people who care for their relatives, for example through specifically designed courses teaching them the relevant skills.

Long-term care insurance funds can also cover the social security and statutory accident insurance contributions of family members who care for relatives. Provisions have also been introduced in the workplace to assist those who care for family members.

The Act on Leave for Carers entitles them to take up to six months of unpaid leave with the continuation of social insurance coverage, whereas the Act on Care in the Family enables carers to reduce their working hours with a certain amount of financial compensation for up to two years.

You must realize this fact: in Germany we have become very used to trusting in the state and its rules and regulations. However, it is time for a change of thinking in our society. Our challenge for the future will be to develop a collective mindset and a new societal concept based on neighbourliness and a mutual readiness to help out with the care of children, the sick and the elderly. In addition to the systems already in place for the provision of care, we will need alternative concepts which promote familial assistance and civic engagement, while at the same time taking into account the specific needs of different religious and cultural communities.

What are good examples of this? A good example of neighbourhood mindedness and mutual assistance may be found in intergenerational homes where the young and old, families and single people, all live together under one roof. The numbers of people living in such homes is increasing slowly but surely in urban areas in Germany. One pilot project in Saxony provides neighbourhood help and is intended to strengthen civic engagement and relieve the burden upon professional service providers. Long-term care funds pay between 100 and 200 euro per month to so-called neighbourhood helpers who provide care and assistance to people suffering from dementia, for example by accompanying them on walks, reading to them, or doing their shopping. The creation of assisted communal living facilities for people with dementia, for example in shared flats has been particularly encouraged. In this example, patients are able to live as independently as possible in communal accommodation. Assistance is provided with everyday tasks according to their needs by outside providers, e.g. carers or relatives.

Only six per cent of dementia patients are admitted to hospital as a direct result of their illness. The most common causes of admission are hip fractures, infections or heart attacks. Acute care hospitals often have difficulties accommodating the special needs and requirements of such patients. Hospitals are organisations on the assumption that patients are able to adapt to their surroundings. Dementia sufferers, however, require a more flexible approach to care than other patients, one which is adapted to their individual needs. Hospitals should therefore establish safe environments with orientation aids, special lighting and colour designs and living areas especially for patients with dementia.

What are our politicians doing about this? We observe, with interest, developments in other European countries, such as the UK, France, Luxembourg, the Netherlands, Norway and certain Swiss cantons, which have already developed national dementia strategies. We are still working on this in Germany (led by the Alliance for People with Dementia in cooperation with the Federal Ministry of Health and the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth).

What should be the main features of the national dementia strategy in Germany? Its initial function should be to describe the aims, priorities and spheres of activity and set incentives for overall developments in the fields of care, medicine and social participation. It should have an integrative function. A basis for constructive dialogue should be established to facilitate a more intensive exchange of information between institutions and other actors in the healthcare sector in order to improve inter-professional cooperation. It should include a steering function in order to coordinate activities and measures taken, solve problems of overlap, and eliminate misgovernance. It should promote the transfer of information. Bearing in mind the efficient use of resources, the national dementia strategy should collect experience which has already been gathered in many areas and organise its transfer. It should have a lobbying function. The national dementia strategy should raise awareness of this topic among the population, leading to its de-stigmatisation and enabling sufferers to play an active role in society. This should help to increase the readiness to take action in the interest of sufferers.

In conclusion, let me attempt to summarise my main points. The full extent of the problem of dementia has already been realised by the medical profession. We are able to describe it, treat it as best we can, and seek improvements in care. However, in a society which is increasingly orientated towards youth and physicality, this problem has not yet been sufficiently addressed. The hedonism which characterises modern, liberal societies often comes into conflict with the self-sacrifice required for the care of the elderly and those suffering from dementia. The deterioration of the family as the focal point of social life promotes social disintegration in old age. Instead of energising mental exchanges with grandchildren and great grandchildren, which used to characterise integration within the family unit, the armchair and television set nowadays symbolise the silent melancholy of old age.

We all have a role to play here, not only as physicians, but also as human beings, not only as priests, but also as spiritual guides, not only as politicians, but also as fellow citizens. And we do this in the full certainty that we will all somehow be touched by dementia within our lifetime. If our responsibility to 'love thy neighbour as thyself' does not suffice in bringing about the necessary structural changes in society, then we should at least not grow tired of reminding each and every individual of the risks that they and their loved ones face. This may not be in accordance with the parable of the Good Samaritan; however, if it is successful then addressing the individual will also benefit the many. 'Love thy neighbour as thyself' will come full circle for the good of dementia sufferers and the elderly, and for the good of us all. ■

2.4 Bolivia

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Psychiatrist,
Consultor of the Pontifical Council for Health Care Workers

The situation can be described by referring to general thinking and the legislative and political response; emphasising the culture and the anthropological value of old age; and describing the facts of the history of the last 103 years of service.

The Legislative and Political Response

Law n. 1886 of 14 August 1998 showed the way in which it was thought that one could protect the elderly; dealt with benefits for citizens over the age of sixty; defined benefits and privileges by which to obtain reductions in the payments for public services (light and water), transport and the taxation of real estate; and guaranteed free medical insurance for elderly people permanently resident in the country.

Subsequently, law n. 3323 of 16 January 2006 stated that the following principles had to be respected: universality, solidarity, fairness and integral coverage for elderly people. It offered services for overall health free to all citizens over the age of sixty who are permanently resident in the country. By this law the Ministry of Health had the task of regularly regulating, coordinating, supervising and controlling the benefits. Funding was obtained with municipal resources and the revenue from taxes on fossil fuels.

A year later this law and the idea that Bolivian society had of elderly people were improved. Indeed, law n. 3791 of 18 November 2007 established the universal old age pension, which was called the ‘dignity pension’, to restore dignity to those people who are dependent because of their age. This is a law of a non-contributory character with a pension for life and the inclusion of funeral expenses. It may seem strange but it is very valuable to understand the thinking of an old person who is worried about what will happen to him or her (and to his or her body) after his or her death.

The law provided for fixing the amount of the pension, an analysis of the data of the beneficiaries and the creation of a ‘pension fund’. It also indicated the sources of funding in order to channel resources.

After this social development and evolution in general thinking, we move forward six years to law n. 368 of 1 May 2013 when the ‘general law for elderly people’ was passed. This law has the task of regulating the rights, the guarantees, and the duties of elderly people, indicating the institutions responsible for their protection on the basis of the following principles: protection, accessibility, non-violence, an intercultural approach, participation, decolonisation, non-discrimination, solidarity between generations, autonomy and self-fulfilment. In this way independent, non-transferable, indivisible and inviolable rights and life guarantees were assured. All of this is not hierarchical, there are no priorities: we are dealing with a set of concepts, values and approaches created within society. This is a network and it has been schematically described here but in the real lives of the elderly people on their own it has to function and must assure their dignity, thereby improving the law that had been passed six years previously.

This social and political situation for the ‘right to a dignified old age’ assures: the promotion of personal freedom in all its forms; integral development without discrimination or violence; the promotion of sufficient alimentation; the promotion of recreational activity; the universal old age pension; access to council housing; involvement in economic development and in programmes involving information on the rights of elderly people; accessibility and the control of architectonic barriers: the promotion of alternative and higher training; and recognition of the authority, the wisdom, the knowledge and the experience of elderly people.

The whole of this process is integrated into programmes that the ministries of the government develop as governmental activity within the ‘Intercultural Community Family Health’ programme which requires, as a key element, team work in health care. This is a new model of care which seeks the involvement of local communities, families and individuals, identifying age groups, illnesses, risk factors and protective factors and assessing economic determinants through a process of social participation.

The Culture and the Anthropological Value of Old Age

In these photographs (figures 1 and 2) we see the Bolivian countryside. Citizens and country folk live in these vast spaces, with such enormous areas, with such intense colours, where, for example, people find their direction immediately without having to remember or calculate the distances that have been covered since setting out. The experience of our own bodies teaches us to root space in existence, to look at things, not like the mould of the real in our minds – there are too many things to register. We have to select and to interpret.

The importance of demonstrating the natural environment, the creation, the vastness of the world where elderly Bolivian people have lived, enables us to draw near and understand how elderly people, because of pain, of sufferings, of illnesses, deal with their stage of life, with their debilitated bodies, with time that comes to an end, that does not stop, but who for this reason necessarily refer to the experience of corporeal space, to space, and who are not in front of their bodies – it is their bodies. They could say 'I am my body'.

To have the experience of eyes that are unable to see, ears exposed to sounds which it is impossible to identify; feeling that the night is a time of the undoing of meaning; living a world that is so large that it is not fathomable, and the principle of reality is frail: this is how a simple county person can experience nothing in all of his or her life and see death with so much responsibility. Or to express it differently, live it with so much diversity.

In this way, the interpretation of the experience of the death of the other affects my own identity of the responsible self. This is a way of seeing how an elderly person can be cared for, or how one understands the time that passes, and how one can face up to death, because in the ultimate analysis this is what one is dealing with when one speaks about old age. In this world facing up to it obliges us to demonstrate the facts.

The History of 103 Years of Service: the Work of the Church

An example: the San Ramon Old People's Home of the city of La Paz run by the 'Little Sisters of Abandoned Old Folk' has reached 103 years of work. Since it was opened it has cared for 8,374 elderly people from all walks of life. Can you see time in this house, in these sisters?

Another example: the old people's home of the city of Santa Cruz where in the same way for many years the value and the dignity of elderly people have been demonstrated in a silent way and over time. ■

2.5 India

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India is the second most populous country in the world with over 1.22 billion people. India is projected to be the world's most populous country by 2025, surpassing China. India supports 17.5% of the world's population. In India the size of the elderly population (>60 years of age) is fast growing and constitutes about 7.4% of the total population and is projected to reach 12.45% of the population by the year 2026. Neurodegenerative diseases occur at any age group but they are more common in the elderly. The commonest neurodegenerative diseases encountered in India are Alzheimer's disease and Parkinson's disease. The prevalence of Alzheimer's dementia is around 1-3% in elderly Indians above 65 years. Most of these diseases are relentlessly progressive and there are no specific treatments to cure them.

Alzheimer's disease usually starts as memory loss and progresses over time to a global cognitive decline. All types of patients from those with mild cognitive impairment to those with severe end stage dementia are seen during clinical practice. The exact prevalence of mild cognitive impairment and early Alzheimer's disease in the population is unknown as many of these disorders are considered a part of normal aging by lay people. As the disease advances most patients become dependent on others for their activities of daily living. The burden on care givers is huge and care giver burn out is common. It is truly a disease of the care giver rather than the patient as many of them lose insight into their illness as the disease advances. It is a painful experience for the close relatives to see their dear ones looking externally normal but unable to remember or speak and behaving weirdly. Most of these demented elderly need a medical evaluation to rule out any treatable causes of dementia and medications to stabilize their memory and to take care of their behavioral problems and sleep. Patients who come to the hospitals are evaluated in detail by bedside tests for memory, a mini-mental status examination and other appropriate neuropsychological tests. An MRI scan of the brain is done for all patients to rule out vascular lesions, tumors, hydrocephalus etc. Blood investigations include thyroid function tests, vitamin B12 level and S.VDRL. Patients are started on memory stabilizing medications like donepezil. Behavioral disturbances and psychosis are usually managed by small doses of antipsychotic medications. Those who reach the hospital usually get the best evaluation and treatment as per standard guidelines. Many patients with a poor socioeconomic status may not come to the physician during the early stages of dementia as many consider loss of memory as a part of normal aging. Most of these patients with dementia are taken care of at home by their spouse and children. Unlike in the West institutional placement is less likely in our country, even in advanced stages of the disease. This may be due to the close family structure, social norms and religious practices, where it is considered a sin to abandon elderly parents to destitute homes. Good and dedicated old people's homes catering to patients with neurodegenerative diseases like dementia are sparse in our country. As most of the population belongs to the low- and middle-income groups it is not possible for many families to afford to place their parents with dementia in an old people's home.

Parkinson's disease commonly affects people over 50 years of age and characteristically results in slowness, stiffness, tremors and falls. Patients with Parkinson's disease can develop behavioral changes, hallucinations, delusions and psychosis later on in the illness. During the initial stages of the disease they can be well managed with medications but at later stages they may need assistance for their day to day activities. There are a group of disorders called Parkinson plus syndromes where patients can deteriorate much faster and may need close supervision and total assistance for day to day living. Managing these patients is extremely difficult and care giver burn out is common. Diffuse Lewy body dementia, frontotemporal dementias, vascular dementias, and nutritional dementias are other types of dementias encountered in the elderly population. Motor neuron disease is another type of neurodegenerative condition that affects the motor nervous system and cripples an individual. Most of these patients are taken care of by their dear ones. Social or governmental support is practically non-existent in developing countries like India. Individuals and families have to arrange for the medical expenses, day to day care and food for these patients. Old age institutions run by nuns and priests are a great solace to elderly people with dementia but the numbers of such institutions are sparse. It is hoped that in the future the scenario will change with more and more day care centers and homes for elderly people with dementia. I think the Church has a huge role to play in care for sick elderly people with neurodegenerative diseases, especially in developing countries. ■

2.6 Israel and Italy

PROF. ENRICO MAIROV
President of the Mount Sinai Association

The 'Global Home Care Services' System

Ever since its birth, human society has turned to medical doctors to look for relief for its suffering. During the age of the great empires fortunate citizens – the nobles and/or the rich – could afford to 'build in their homes' hospitals as they so required. The less fortunate were looked after in poor institutions to which in general people went to die.

During the modern epoch, with the end of the medieval period, the idea began to be developed of the need to care for sick people in an increasingly appropriate way. During these centuries, religious hospitals – starting with Catholic ones – increasingly dedicated themselves to caring for *ordinary* people and not only the *fortunate*.

At the beginning of the twentieth century, in the industrialised world there already existed hundreds of hospital institutions in local areas and practically the whole of socio/health-care care was provided by them. After the Second World War the important increase in the number of human beings and the increase in life expectancy raised for mankind the problem of overall and integrated care for chronic patients. In the middle of the 1960s, in such major industrialised countries as Canada, the United States of America, the United Kingdom, France, Italy, Germany, the countries of northern Europe and Japan, experimental projects began to be implemented to delocalise socio/health care help for these patients from hospitals to their homes. In the middle of the 1980s, in Israel a major analysis began of the national socio/health-care system. Within the framework of this system, between 1985 and 1991 there developed a process involving the implementation of home care for chronic patients. As a consequence, with the important development of the whole of the health-care system – the Organisation for the Protection of Health, Hospital Companies and the System for Traumas and Emergencies – as well, the service of home care was established as a 'global home care services' system that was offered by the individual organisations for the protection of health to the whole of those members of the population who were in need.

The services involving home care that have developed throughout the Western world over the last thirty years are variegated in character and seek to meet the needs of chronic patients. At the present time, a strategic integrated system for 'long-term care patients' does not exist in any country of the world, not least because health-care systems have remained strongly centred around hospitals. In this way, two major problems have been created: 1. an explosion in costs in industrialised countries where millions of chronic patients are admitted to hospitals in an inappropriate way; 2. a major shortage of both social and health-care services in developing countries where the population is obliged to migrate towards hospitals which are not easy to reach.

The rapid development of the process of globalisation which allows the possibility of travelling and communicating increasingly rapidly throughout the planet has created the need to have a socio/health-care system available to everyone that is able to guarantee the safety of the human population. A universal and supportive global system has to include the dimension of home care as one of its integral parts. In this way, there is also constructed a rational economic balance which allows appropriate care to be assured to everyone.

The modern discipline of 'global home care service' was developed in the middle of the 1980s in the metropolitan area of Tel Aviv in Israel when one of the four existing organisations for the protection of health (OPH), the MEUHEDET (the Union), began to engage in the implementation of home care. In an epoch when mass computerisation and cell phone telecommunications were just beginning, the work of the first team for home care had to deal with a health-care system that was exclusively centred around hospitals and the use of paper and pens for routine activities.

During the initial stage of the work, four fundamental systems were created:

1. The support system for an OPH in hospitals with the figure of the 'selector': the selector administers and meets the patients of his or her own local area institution who are admitted to hospital. The selector, together with the hospital team, assesses the suitably of admissions and the possible need for the activation of post-acute care, through home care activity as well.

2. The system for the management and activities of home care which includes a medical doctor, a nurse, a physiotherapist and any other professional figure that is needed for the appropriate implementation of home care itself.

3. The system for decisions about care to be applied to each individual patient based upon specific clinical, organisational and economic algorithms

4. The system for the planning and checking of the cost/utility ration and the quality of health-care services.

A new approach to work between the home-care team, the hospital context and the family doctors engaged in work in the local area was achieved. This approach contributed in an important way to implementing two fundamental processes, which are the discharging and the readmission of chronic patients.

In this way, the following goals were achieved in a small space of time:

1. Excellent cooperation between the local areas and hospitals as regards the innovative concept of the adaptation of the methods of the DRGs with the development of the idea of contractual agreements between the OPHs and the hospital companies.

2. An important decrease in unsuitable access to hospitals and a significant decrease in useless admissions.

3. Strategic training pathways for workers in the health-care system as regards the new system that was being developed.

4. An important increase in the satisfaction of people as regards the new service of home care within the new nascent model of the *health-care system*.

With the widespread introduction inside the health-care system, and the development of, communications by mobile phones, the quality of the service that was offered to patients in home care greatly increased and this allowed extremely qualified immediate responses for patients and their families

The new service was steadily integrated into the emergency services of local areas, with the creation of what we today know by the strategic term relating to health-care organisation and economics of 'intermediate structures'.

Intermediate structures, which include local-area emergency services and home care, and which are the strategic guarantors of the appropriateness of this mature health-care system, assure through their activities the immediate saving of lives in danger and a great wealth of home services for chronic patients, with the ending of the waste of useless services and inappropriate admissions due to the 'reactionary inertia' of the old system, the anomalous approach of defensive medicine, scarce and erroneous education in medical schools, and the 'lazy routine' of the health-care teams.

The energy that is needed to advance the health-care service towards the achievement of a complete system is provided today by a major impetus due to basic research, clinical research, the development of technology and the explosion of costs for the maintenance of the health-care service itself. Today these costs throughout the Western world are enormously greater than those of the health-care system in the State of Israel and, as was pointed out by the OECD report of December 2012, this system is of fundamental importance as a point of reference for all the decision-makers who at an international level have to provide suitable answers to their populations, guaranteeing qualified answers of a high level to health problems.

Strengthened by this experience and also by the creation of the ARES (Regional Company for Health-Care Emergencies in Lazio), and the reorganisation of the emergency section of the regional government of Veneto, we drew up an operational proposal to be achieved through a strategic experiment: the Intermediate Structures and the School of Training for the Management of Health-Care services in Relation to Traumas, Emergencies and Conventional and Non-Conventional Maxi-Emergencies. Intermediate structures and a school of training can be established in northern Italy with the guidance of the scientific centre of the Pontifical Council for Health Care Workers and with the operational application of twinning between the Good Samaritan Foundation and the planned Mount Sinai Foundation. The institutions that exist in the area of the northern region will be an operational theatre for the experimental establishment and implementation of the new components of the system. This new organisation can act as a trigger for the development of the health-care service towards a complete health-care system. The new system will be an incubator for the transformation of the network of world Catholic institutions into an operational system made up of components of the same network. The directive centre of the Pontifical Council for Health Care Workers will achieve during the initial stage a new approach towards countries of the Mediterranean and the Middle East, offering them operational cooperation through their health-care models. This new approach between the Pontifical Council for Health Care Workers and the health-care services of various countries of the Mediterranean will take place through the sending to their greatest experts a proposal to construct together a network of relationships regarding various aspects of research and organisation.

Neurodegenerative Illnesses – Dementia

The major increase in the number of chronic patients that has taken place in recent decades has also caused a significant increase in the number of individuals with neurodegenerative illnesses. Parkinson's disease, various aspects of dementia, from the vascular to cerebral organic syndrome and the dementia of Alzheimer's disease, have added throughout the world today a large number of new patients for whom a revolutionary new approach has to be developed.

Medical science still knows very little about the brain and the human nervous system. Progress in our knowledge about the pathologies that afflict the major life systems (the cardio-circulatory, the respiratory, the immunological and the metabolic) has been very significant in recent decades. We have developed sophisticated pathways as regards prevention, diagnosis, therapy and rehabilitation with respect to cardiovascular problems, oncologic pathologies and the principal metabolic problems. As regards everything that concerns the behaviour of the human brain and the pathologies connected with it, despite important attempts to find access keys to their understanding, hitherto we have not been able to obtain equally successful results.

This problem – the lack of appropriate information on knowledge about the human brain – causes deep frustration in the human population and above all in the scientific world The explosion in costs as regards the management of neurological and behavioural pathologies forces our society to take decisions that have a dramatic impact through the *ethics of health-care expenditure*.

Within the context of psychiatric behaviour and illnesses, innovative medical products have been identified which are only of a palliative character because of a lack of knowledge about the aetiology and the physiopathology of these illnesses. As regards the study of, and research on, the human brain we are very much behindhand and there is a lack of operational instruments that are able to help our inquiries. This delay is responsible for the malaise of tens of millions of people and their family relatives who have to deal with a catastrophic situation that we term 'dementia'

Dementia is a 'dark malady'. There are suppositions about its origins. Few statistical calculations exist as regards its diagnosis and this forces decision-makers to 'navigate on sight' in order to look for economic solutions to the approach to this situation.

In recent years care systems have been adopted which are different from the usual admissions to hospital. Pushed forward by the great increase in the number of patients with dementia, the most evolved and modern health-care services have begun to invest in different organisational methods as regards care for patients with dementia. These methods take on the fundamental concept of intensive therapy where a certain number of grave patients who have been admitted to hospital are followed from a central point which constantly checks the vital functions of these patients.

The possibility of placing a patient with dementia outside the walls of a hospital and at the same time assuring that he or she comes to no harm is based on technological and scientific solutions that relate to organisation, pharmacological control, social assistance, telecommunications and an appropriate economic model. A practical example can be illustrated in the following way: a patient with dementia of any kind can be managed in his or her own home thereby assuring him or her appropriate home care which is based on the following points: 1. planned visits for medical examinations; 2. visits of nurses with a plan for activities that follows the specific social-care needs of patients and visits by social workers in order to assure social-environmental factors which are necessary to the daily lives of patients and their families: 3. a physiotherapeutic approach for a suitable conservation of the movement of the patient; 4. a cognitive approach which includes home-based initiatives for the maintenance and strengthening of cognitive conditions; participation in 'day centres' for chronic patients with services and stimuli for cognitive activity; 5.suitable psychological support for families and the environment of patients; 6. the use of modern technologies of geo-location and televideo-cameras which allow a 'specific health-care call centre' to follow the pathways of patients and both at home and when they go outside their homes; 7. when necessary the use of a permanent 'care-provider' who follows the patient when the situation becomes worse; 8. when this is needed because of the deterioration of conditions, the patient is admitted to special long-term institutions; and 9. the pathway of prevention as regards these kinds of pathologies is of fundamental importance in identifying the initial symptoms.

The context in which the process of global home care services is developing is that of chronic illnesses. The pathology of dementia is an important component of these illnesses. Unfortunately, the lack of an integrated social/health-care system does not yet allow a suitable training of social/health-care workers, the same individuals who are afflicted by these pathologies and their family relatives, so as to enable the identification in a short space of time the onset of illness. The major lack of therapeutic instruments also does not help human society to deal with this phenomenon. Given that the forecasts refer to an increasing number of sick people of this kind in the future, we have to equip ourselves with instruments suited to care and assistance for these sick people, starting with the structures of advanced home care.

Organisational Proposals for the Creation of a Directive Centre in Rome for the Global Health-Care System

As regards the work to implement a universal health-care system, we have to implement a first stage which is of fundamental importance: the creation of the 'High Command of Health Care of the Holy See'.

The High Command would be made up of a certain number of people who would respond in a disciplined, efficient and effective way to the needs of the service and to measures advanced by those who lead it.

The highest figure and his or her staff would have available to them two strategic structures for the management of the overall system: 1. a vertical structure made up of a head for each continent of the world matched by the heads of individual countries; 2. a horizontal structure made up of the heads of various Orders who would intersect in their activities with the vertical structure.

In this way, there would in fact be achieved a single structure in a network with narrow parts that would allow an efficiency and an efficacy involving a rational, logical and modern management.

Overall, the people involved in this structure must be trained to act with an organisational logic which is based upon the ethical discipline of achieving the goals of human health. The difference between the workers of this and any other structure is precisely this: their training and the logic of their provision of service would be based upon the conceptions of ethics that govern the relationship between a medical doctor and his or her patient. It is not enough to know the traditional pathways of medicine – such as prevention, therapy and rehabilitation – which regulate the daily medical practice of each health-care worker guided by the work of a medical doctor. Building on the existential platform of this knowledge, the structure that includes the knowledge that is needed for the modern and operational management of the complex organisation of health care is of fundamental importance.

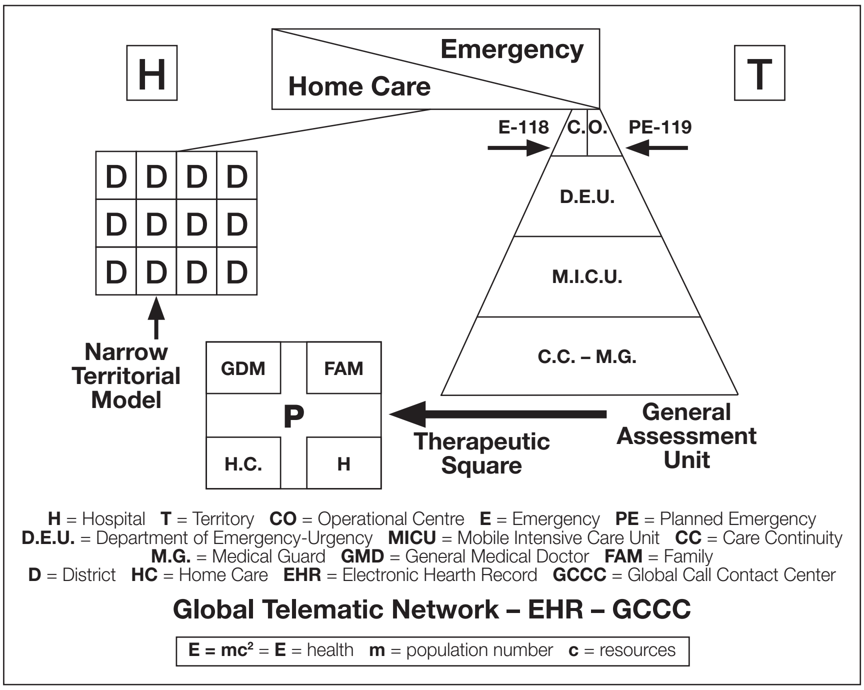
The management of a health-care system is not – as was erroneously thought for a long period of time – mere economic-commercial management: the management of a health-care system is based upon fundamental ethical knowledge which in its turn is based upon the principle of science and conscience which support the managerial capacities of a medical doctor through an in-depth study of planning, control, research and development and other important directions of the system of daily life. The qualities required of a medical doctor who manages a health-care system are vision, a capacity for team work, optimism, capacities for communication, the charisma of a leader, a readiness to invest constantly in research and development, and the courage to address difficult situations and search for ethical-scientific solutions that are coherent and appropriate.

The identification and the choice of the people who will make up a strategic team for the management of a system such as a health-care system is of fundamental importance and pre-supposes instruments for analysis and assessment of the highest quality. The training of the people who are chosen is also extremely important because from the first moment it is necessary to stimulate and obtain reciprocal interest and cooperation on the part of all those individuals who are taking part in the achievement of the system. For this reason, it is also important to begin the pathway of choosing and training which is a precondition to the decision-making leadership constructing a 'new team'.

It is useful at this stage to concentrate on brief training but at the same time training that is incisive and effective as regards knowledge of the fundamental concepts of the health-care system. The benchmark with the Israeli health-care system – one of the best organised such systems in the world – is important specifically because of these characteristics. Together with this, it is also very important to 'inject a curiosity to know' and thus to know how to develop the new global system 'all together'. If one takes into consideration the fact that in the world there are about three hundred countries in the five continents and a comparably important number of religious Orders, a matrix structure emerges with a very high number of people in critical and strategic positions to which to apply the process of training, management and research and development of the system.

Following this pathway together with the constant training of 'medical knowledge', we will be able to achieve a 'process of ongoing training' as regards knowledge of health-care organisation. In this way, important floating stock is created for the great world of social/health-care workers of the Holy See who will acquire new knowledge about the organisation of health care and their own cultural capacities directed towards the surrounding environment as well will grow. It follows that this interface between the world of health-care workers and other people will increase knowledge in a significant way and will achieve a rapid and modern approach to communication between human beings.

The method of modern interaction between workers in the health-care system and other people is one powerful locomotive for the promotion of the knowledge that is needed for survival. To work well, people who have as a reference point the Pontifical Council for Health Care Workers have the right and the duty to be trained adequately with efficient methods and with an optimal cost/benefit ratio. What we know by the term 'industrial revolution' and which allows us increasingly to have technologies that facilitate life, must be integrated with the process of 'intellectual progress' which provides us with the ethical platform on which are integrated faith and scientific knowledge, allowing an improvement in the quality of life of the human species.



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2.7 United States: A Best Practice in Caring for People with Neurodegenerative Aging Bridging the gap

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> *"Do not cast me off in the time of old age; forsake me not when my strength is spent."*[1]

Background

In the United States, the population has surpassed 315 million with 40 million over the age of 65.[2] Almost a third of these have neurodegenerative conditions including Alzheimer's disease, Parkinson's disease, and multiple sclerosis among others.

The number of disabled living in community has increased significantly – largely because of declining rates of institutional use. Compounding this problem are changes in traditional family structure – a decrease in the size of families, divorce or cohabitation instead of marriage, and family fragmentation with adult children living at a great distance from their parents. The problem of caring for such a large population with the neurodegenerative problems of aging is daunting

Nevertheless, 90% of those with disabilities over the age of 65 receive either family care or formal paid care in the home. Further, some of the deficit in direct human assistance by families has been supplanted, at least in part, by the use of assistive devices from walkers to home elevators to help with personal care and independent activities of daily living. In fact, almost half (46%) of those living at home rely on assistive devices – an increase of 155% in the 20 years between 1984 and 2004.[1]

Like such families, my wife and I were privileged to care for both of my parents in our home. My father was a WWII veteran. My mother was a Red Cross volunteer during the war and met my father in Bavaria at the war's end. Three months later they married. My father ultimately retired as a brigadier general and enjoyed several subsequent careers. Yet in his late 70s, he was increasingly disabled with Parkinson's and needed help beyond what my mother could provide. My wife and I remodeled our home adding a suite for my parents including a walk-in shower as well as elevator-access making the home functionally one level.

While none of us would have wished for my father 's neurodegenerative illness with its inherent challenges and adjustments, our whole family was blessed with the need to help one another. In fact, during their several years of living with us, we had more time together and made more memories with our children's grandparents than we'd had in the 20 preceding years!

Despite optimal medical and family care and support, my father's disease progressed. He ultimately died of complications within a few months of this hospital-based, Christmas visit.

My parents were very close – both in life and in death. After 57 years of marriage, and only three months after my father died, my distraught mother was in both physical and mental decline – yet, still very much loved as in this special lucid moment with her "holding court" in her own living area within our home surrounded by two of her children and many of her grandchildren. She died within a week of this photograph – again, supported around the clock by her children, grandchildren and closest cousin.

Yet, many families do not have the resources or capacity to provide this level of support. There remain 10% of the severely disabled unable to be cared for at home. What options are now available for this large segment of our population?

This paper describes one approach that involved the creation of community-based, staged-care system with an unusual and innovative (at least in the United States) collaboration of the secular and spiritual realms.

A vision emerges

In 1993, Father Michael Maslowsky was serving as Director of Pastoral Services for the Archdiocese of Portland, Oregon. In addition to those responsibilities, he also was given charge of St. Anthony's parish—a declining and aging, faith community in a transitioning section of the city. St. Anthony parish had long since closed its parish school and faced a dwindling population of parishioners who worshiped in the basement of its former school. The Archdiocese anticipated either closing the parish or transferring it to another faith community. Father Maslowsky was to assume the task of either closure or transition.

However, impressed with the fervor of his remaining parishioners, Father Maslowsky's thinking evolved in a different direction. He began to consider not only the needs and potential of his parishioners but the surrounding neighborhood, Catholic or not. He wondered how, as Christ's faith community, St. Anthony parish might respond to a fragmenting society and the increasingly needs of frail, low-income seniors. Could a revitalized parish provide housing and care for the needy elderly while stimulating its own renewal in faith and service?

Father Maslowsky had earned his Doctorate in Theology (STD) here at the Gregorian University. After his ordination and during his doctoral studies in Rome, he provided pastoral services in various Italian parishes. His summers were spent as a substitute priest in villages in rural Germany. Through these various experiences he observed the support and care, usually parish-centered, possible in small communities.

Father Maslowsky saw the Church as Christ's community of faith – essentially at the heart of society. He also saw Assisted Living, then an emerging care alternative for the disabled or elderly, as an opportunity to bring the faith community to those in special need of hope and love. Assisted living had been conceptualized and first implemented in the city of Portland, Oregon in the early 1980s. By the 90's it was beginning to flourish as a viable alternative to placement in nursing homes.[3] Father Maslowsky recognized the potential synergy between the Church's compassionate community and assisted living's innovative care.

With his successful legal and business background, Father Maslowsky was able to bring together a group of diverse and talented individuals to form a non-profit corporation – Village Enterprises. These men and women committed their considerable energies to the vision of a supportive, faith-centered village that would care for the low-income elderly in various levels of need.

Implementation

After two years of dialogue, planning as well as significant financial and legal process, the implementation of Father Maslowsky's vision began. Village Enterprises and St. Anthony parish collaborated in the simultaneous design and construction of both St. Anthony Village and a new St. Anthony Church and Parish Center. The parish's aging school building with its basement worship space was razed and the entire property began a remarkable transformation. In 1999, with Catholic faith as a foundation and an innovative care community as a goal, Village Enterprises inaugurated St. Anthony Village as the first of what would be four, faith-based senior communities in Portland, Oregon.

Today St. Anthony's Village is home to 127 residents in Independent, Assisted Living or Memory Care. It is a well-staffed facility with a solid sense of community and real respect between residents and caregivers. A wide range of activities, organized by a full-time activity director, is available daily to residents. For the more adventuresome there are excursions such as this day trip to Multnomah Falls, a wonder of nature carved out of the Cascade Mountains.

Although St. Anthony Village serves and employs persons of varying beliefs, it is our Catholic faith, with its tradition of service and its mission of care that lies at the heart of the Village. Each day Mass is celebrated literally steps from residents' apartments and all residents are invited to share in the life of a revitalized and vibrant parish community. For those quieter moments there are lovely areas available to relax and to pray.

Expansion of the Vision

A significant addition to St. Anthony Village occurred a year after it opened its doors with the decision to build a multigenerational component. In 2000, as a Millennium expression of faith, Village Enterprises constructed a childcare center. Village Enterprises subsequently donated the childcare building and its land to the parish. Today the St. Anthony Child Developmental Center continues to provide affordable childcare to neighborhood families on an ability to pay basis. While the Child Center provides a small income to the parish, the greater benefit for residents and parishioners alike is the laughter and joy of children. The Center also provides children with both scheduled and ad hoc interactions with Village residents through a variety of activities. "Adopted grandparents" read to children, entertain them, or share with them the wonders of gardening.

An essential part of the Village community is St. Anthony Village's two Memory Care cottages. To respect the identity and dignity of the 24 cottage residents each resident's apartment is decorated and maintained as their individual home. Familiar furniture, pictures and memorabilia are reminders of the residents' lives and loves. Among the activities offered to residents, music is a frequent and important part of their care. At least in the short-term,[4,5] music has been shown to clean away cobwebs and unlock dormant aspects of memory and personality.

Expansion in other locations

In 2002 Assumption Village, modeled after St. Anthony Village, became Village Enterprises' second senior community. Built on the site of a former parish in an underserved area of North Portland, Assumption Village provides independent and assisted living to 110 low income seniors. Like its sister village, Assumption Village's physical and spiritual center is its Catholic chapel and daily Eucharist.

To respond to the housing needs of seniors who can care for themselves, but cannot maintain a private home, Village Enterprises constructed two other facilities, Sacred Heart Villa and Villa St. Margaret. Residents at either of these senior Independent Living facilities do not receive daily assistance. However these residents can transition easily to assisted living or Memory Care at St. Anthony Village or Assumption Village should they so need or desire. At each of these communities residents maintain their independence for as long as possible due in part to the friendship and faith their share. In fact, nine of Villa St. Margaret's sixty residents are ninety years of age or older.

Theological imperatives

All of us as Catholics have a duty to care for our aged brothers and sisters, whether able or disabled, as each elderly individual is a person created in the image of God.[6] In our likeness to God we are relational beings and we are called to live our relationships in approximation of the divine love. Every one of us is deserving of care whether hungry, thirsty, naked or sick.[7] We best reflect our relational God when we emulate his universal love. We most profoundly realize our own relational nature in our particular acts of love.

Scripture repeatedly exhorts us to provide for the elderly. St. Paul calls us to honor "an older man" and "appeal to him as father" and also to "Honor widows".[8] Further, the book of Leviticus specifically directs us to "…rise up before the grayheaded and honor the aged. [9] While families have an obligation to provide for their aged members,[10] and this is, indeed, happens in the majority of cases, St. Paul also describes the special responsibility of churches. In his 1st letter to Timothy, he writes "…the church must not be burdened, so that it can help those who are widows indeed".[11]

Conclusion

Having behaviorally followed the exhortations woven throughout sacred Scripture, St. Anthony's parishioners and all those who have cooperated in their mission have clearly developed a "best practice" in addressing the needs of the aged and infirm with no family or whose family is unable (or unwilling) to provide support and care.

Father Maslowsky's vision for a once declining parish is fully realized. The success of St. Anthony's Village is reflected in the eyes of both young and old. It has become a multi-generational community with Independent, Assisted Living and Memory Care for seniors, a Children's Developmental Center, and a vibrant Catholic faith community. A number of other parishes and dioceses have or are considering similar projects. Should they consider this concept, they should also appreciate the importance of placing Christ's faith community at the center of their care community; a Christ-centered focus ensures a best practice of compassionate care for those with neurodegenerative processes.

"They still bear fruit
in old age: they are ever full
of sap and green"[12]

Notes

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[6] Genesis 1:27.

[7] Matthew 25:37-38.

[8] 1 Timothy 5:1-2.

[9] Leviticus 19:32.

[10] 1 Timothy 5:8.

[11] 1 Timothy 5:16.

[12] Psalm 92:14.

SIXTH SESSION

PREVENTIVE ACTIONS AND POTENTIAL ADVANTAGES OF TECHNOLOGICAL PROGRESS

1. Alimentation and Physical and Intellectual Activity

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Throughout evolution humans and animals alike have always sought food to survive. Alimentation supplies us with several life-supporting substances including proteins, fats, carbohydrates, vitamins and minerals. These substances are the main sources of energy for all body processes. Recent abrupt changes in dietary habits have occurred worldwide. Overnutrition leading to obesity is widespread and many parts of the world are still exposed to severe involuntary caloric restriction due to food scarcity. It will be appropriate to clarify, in the final section of this presentation, the magnitude and impact of these changes. Let us first explore the links between alimentation, physical and intellectual activity.

Alimentation: the Concept of Energy Balance Equations

Alimentation (food intake) provides us with energy (energy intake) that is not totally spent (energy expenditure). The balance between energy intake and energy expenditure determines energy stores. The energy balance equation depends on its various nutrient balance equations namely protein, lipid and carbohydrate.[1]

Protein balance

One gram of protein provides 4 kilocalories. Protein intake is usually about 15% of calories and the protein stores in the body represent about one third of the total stored calories. The protein stores increase in size in response to such growth stimuli as *physical training*, weight gain and some hormones (growth hormone, androgens) but do not increase simply from increased dietary protein.[1,2]

Carbohydrate balance

Carbohydrate is usually the main source of dietary calories. *One gram of carbohydrate provides 4 kilocalories*. Its intake is about 50% to 55% of calories and may be higher in some countries. The daily intake corresponds to about 50%-100% of the carbohydrate stores compared to 1% of protein and fat. Dietary carbohydrate stimulates both glycogen storage and glucose oxidation and suppresses fat oxidation. That which is not stored as glycogen is oxidized (not converted to fat), and carbohydrate balance is achieved.[1,2]

Fat balance

In contrast to protein and carbohydrate, body fat stores are large and fat intake has no influence on fat oxidation. Fat intake is about 30%-35% of calories. *One gram of fat provides 9 kilocalories*. As with protein, the daily fat intake represents less than 1% of the total body energy stored as fat, but the fat stores contain about six times the energy of the protein stores. The fat stores are the energy buffer for the body and daily surplus or deficit in energy intake is directly translated into surplus or deficit in fat mass. In conditions of overfeeding the entire excess fat intake is stored as body fat. Energy balance is the driving force for fat oxidation. When it is negative (i.e. energy expenditure exceeding energy intake), fat oxidation increases.[1]

Let us summarize by saying that under physiological conditions, fat is the only nutrient capable of maintaining a chronic imbalance between intake and oxidation, thus directly contributing to the increase of adipose tissue. Carbohydrate and protein influence adiposity indirectly by their contribution to overall energy balance and thus fat balance

Alcohol balance

It has been shown that in healthy individuals the fate of ingested alcohol is oxidation and not storage (as fat), and therefore perfect alcohol balance is achieved.[1,3] Alcohol, in the same manner as carbohydrate and protein, diverts dietary fat away from oxidation and toward storage and therefore indirectly promotes fat deposition. One gram of alcohol provides 7 kilocalories.

Alimentation: energy expenditure

There are four major components of daily energy expenditure, i.e., resting metabolic rate (RMR), thermogenesis (T), spontaneous physical activity (SPA) and voluntary physical activity (VPA).

Resting metabolic rate (RMR)

The RMR is the energy expended by a subject resting in the fasting state under comfortable ambient conditions. In most sedentary adults, RMR accounts for approximately for *60%-70% of daily energy expenditure*.[4] The major determinants of RMR explaining almost 80% of its variance are: fat-free mass, fat mass, age, gender and genes. Women have lower RMR (effect of sex hormones on metabolic rates) compared to men (100 kcal/day less). RMR decreases with age probably due to decreases in fat-free mass (1-2% decrease per decade). Some of the remaining variance of RMR is explained by family membership, suggesting that RMR is at least partly genetically determined. Finally, it has been suggested that the variability in RMR after adjustments for differences in fat-free mass, fat mass and age, is related to variability in body temperature, indicating that body temperature could be a marker for a low or high RMR.

Thermic effect of food (TEF)

The thermic effect of food (TEF) is the increase in energy expenditure observed after the ingestion of a meal. TEF accounts for *5%-15% of the daily energy expenditure*.[5,6] Many factors influence the TEF: meal size and composition, palatability of the food, time of the meal as well as genetic background, age, physical fitness, and sensitivity to insulin. However, individual differences in TEF can only account for small differences in daily energy expenditure. Decreased thermogenesis is a very unlikely explanation for significant degrees of obesity.

Alimentation: fiber, minerals and vitamins needs for a balanced daily diet

Most nutrition experts recommend that most individuals should consume 25-35 grams of dietary fiber daily. Recommended daily intake of vitamins encompasses vitamins B-complex, B1, B2, B3, B6, B12, C, D, E, K that can be found in food as well as minerals and supplementation may be needed in certain medical conditions

Alimentation and physical activity

What is physical activity?

Physical activity has been defined by Caspersen *et al.* as 'any bodily movement produced by skeletal muscles that requires energy expenditure'.[7] Physical expenditure is the second major component of total energy expenditure after RMR expenditure (60%-70%) and before the TEF (5%-15%) and accounts for 20%-30% of energy expended through some type of 'physical activity' which can be then subdivided into energy expended in general activities in daily living (such as bathing, feeding and grooming), occupation activity, sporting and other leisure activities, transportation activity and household and caretaking activities (including home repair). The relative contribution of each of these components can vary considerably both within and among individuals and populations.[8] In addition to quantifying physical activity based on the amount of energy expended, physical activity can be quantified based on the manner in which energy is expended.[8] Physical activity can be measured according to its effects on different systems of the body by assessing attributes such as aerobic intensity, muscular resistance, degree of weight-bearing, and range of motion and flexibility involved. A daily walk of thirty minutes is the beginning of being active.

There is strong evidence that physical activity reduces the risk of diabetes, cardiovascular diseases and increases life expectancy. It is an essential part of life regardless of age and gender. It requires specific dietary needs.

Dietary needs for physical activity

During exercise the energy demand of the working muscles is met by breakdown of intramuscular glycogen and triglyceride stores as well as by an increased supply of glucose from the liver and free fatty acids from extramuscular triglycerides stores. Glycogen, glucose and triglycerides stores depend strongly on carbohydrate intake.[1,8] The contribution of carbohydrate to overall energy delivery increases with exercise intensity. The main fuel needed for energy during exercise comes from carbohydrate. Protein and fat oxidation may occur when the carbohydrate stores are low (high intensity in physical activity).

Consequences of physical inactivity

There is little doubt that reduced physical activity is a cause of obesity. The secular increase in obesity parallels the increase in sedentary lifestyles and the increase in diabetes mellitus. Data from the United Kingdom show that the prevalence of obesity has dramatically increased over the past three to four decades despite a marked decrease in energy intake, suggesting that physical activity has decreased even more during the same period.[9] In many other parts of the world, physical activity has dramatically decreased over the past few decades with the increased number of cars per household and the increase in the numbers of hours spent in front of television sets or personal computers.

Globally, around 31% of adults age 15 and over were insufficiently active in 2008 (men 28% and women 34%) according to the World Health Organization

(WHO).[10] The highest rates were found in the WHO Region of the Americas and the Eastern Mediterranean Region. In both these regions, almost 50% of women were considered insufficiently active, while the prevalence for men was 40% in the Americas and 36% in the Eastern Mediterranean. Physical inactivity has been identified as the fourth leading risk factor for global mortality, causing an estimated 3.2 millions deaths globally. These premature deaths are due to an increase risk of cardiovascular diseases, diabetes, colon and gynecologic cancers including breast cancer. Osteoporosis leading to increased risk of hip or vertebral fracture is strongly associated with decreased physical activity.

Recognizing the opportunity for reducing deaths and diseases worldwide by improving diets and increasing levels of physical activity, the World Health Assembly adopted the WHO Global Strategy on Diet, Physical Activity and Health in May 2004. This Strategy provides recommendations for Member States, WHO, international partners, private sector, civil society and nongovernmental organizations on the promotion of healthy diets and regular physical activity for the prevention of noncommunicable diseases (NCDs) such as diabetes, cardiovascular diseases, osteoporosis and cancers.

Furthermore, the Global NCD Action Plan 2013-2020 recently endorsed by the WHO Assembly (2013), includes a set of actions to promote healthy diets and physical activity, and to attain 9 voluntary global targets for NCDs including ones on diet and physical activity to be achieved by 2025 (resolution WHA 66-10).

Alimentation and intellectual activity

Intellectual activity: a biochemical process?

Intellectual activity may be defined as an activity that requires lightning-fast electrical impulses between areas of the brain to make connections, find meanings, speculate, measure, understand and finally make decisions.[11] It is definitively a biochemical process that involves approximately an interplay between 100 billion brain cells or neurons. Intellectual activity is driven by neurons. In order to function properly, they need nutrients such as carbohydrates, protein, fat, as well as micronutrients (vitamins, minerals) and water. These substances are used by the neurons for different purposes including the set-up of the biochemical language between connected neurons (neurotransmission) via hundreds of neurotransmitters which are manufactured in the brain – all from the food we eat. What are the respective roles of these different nutrients?

Cognition and energy metabolism

The brain consumes a considerable amount of energy relative to the rest of the body. It has been estimated that the brain may consume up to 50% of the daily carbohydrate ingested. It is therefore understandable that the mechanisms involved in the transfer of energy from foods to neurons are likely to be fundamental to the control of brain function.[12] Energy metabolism and synaptic plasticity are important processes tightly implicated in the control of brain function such as cognitive function. Molecular mechanisms involved in this function can be positively or negatively influenced by bad or good foods.[12,13] For instance, dietary omega-3 fatty acids stimulate neuronal plasticity and can therefore affect synaptic plasticity and cognition.[13] Disturbances in energy homeostasis have been linked to the pathobiology of several mental diseases and so dietary management is becoming a realistic approach to try to treat psychiatric disorders. Numerous studies have found that there might be an association between abnormal metabolism (type 2 diabetes, obesity and metabolic syndrome) and psychiatric disorders (manic depression, schizophrenia).[14]

Effects of nutrients on cognition and memory

Several dietary components have been identified as having effects on cognitive abilities. Dietary factors can affect multiple brain processes by regulating neurotransmitter pathways, synaptic transmission, membrane fluidity and signal-transduction pathways. Some selected nutrients can positively affect cognition and emotion.[11]

Omega 3 fatty acids, for instance, can improve cognitive decline in the elderly. Saturated fat, B vitamins, vitamins D, E, choline and combination of antioxidant (C, E, carotene) have shown to have beneficial effects not only on cognition but also on memory performance.

In contrast to the healthy effects of diets that are rich in omga-3 fatty acids, epidemiological studies indicate that diets with high contents of trans and saturated fats adversely affect cognition.[13] Animal studies that evaluate the effect of junk food, characterized by high contents of saturated fat and sucrose, have shown a decline in cognitive performance after only 3 weeks of dietary treatment.[15] These findings suggest that diet had a direct effect on neurons that was independent of insulin resistance or obesity. More alarming is the fact that this diet elevated the neurological burden that was associated with experimental brain injury.

Antioxidant foods

The brain is highly sensitive to oxidative damage because of its high metabolic load and its abundance of oxidizable material (polyunsaturated fatty acids forming the plasma membranes of neural cells).[11] Various micronutrients with an anti-oxidant capacity that has been associated with mitochondrial activity have been shown to influence cognition. Alpha lipoic acid has been shown to improve memory deficits in animal models of Alzheimer's disease.[16] Vitamin E has also been implicated in cognitive performance in older individuals.[17] Antioxidant foods may protect the brain from lipid peroxidation and nitric-oxide-based radicals. In summary excess calories intake may impair cognition by inducing fat oxidation. Antioxidant foods have a far more protective effect.[11]

It is now clear that specific nutrients positively influence cognition by acting on molecular systems or cellular processes that are vital for maintaining cognitive function. The effects of diet on the brain are integrated with the actions of other lifestyle modalities such as physical activity. Although several dietary components have been found to have positive effects on cognition or intellectual activity, a balanced diet is still the cornerstone for any dietary supplementation.[11]

Healthy alimentation: Mens sana in copore sano

I may introduce my concluding remarks by using this Latin quotation, a healthy mind in a healthy body thanks to a healthy alimentation. The physical and intellectual activities are both tightly interconnected and both need energy from good food for a good performance. What are the recommendations?

The World Health Organization has made the following recommendations for both individuals and populations

1. Eat roughly the same amounts of calories that your body is using. A healthy weight is a balance between energy consumed and energy that is burn off.
2. Increase consumption of plant foods particularly fruits, vegetables, legumes, whole grains and nuts.
3. Limit intake of fats, preferring the healthier unsaturated fats to saturated fats and trans fats.
4. Limit the intake of granulated sugar preferring complex carbohydrates to refined sugars.
5. Limit salt/sodium consumption from all sources and ensure that salt is iodized.

There are numerous sound recommendations from different medical associations, schools of public health, various health agencies and so forth. But there are also numerous barriers that explain why these recommendations are not followed and poverty is one of the most important of them. Even in developed countries malnutrition prevails among elderly people in different institutions. The numbers of those affected vary between 5%-10 % of the total elderly population living in the community.(18) About 60% of hospitalized older adults (age 65 and more) and 355-85% in long-term facilities are experiencing malnutrition in the USA. The elderly population is expected to double by 2030 according to the NIH and reach about 72 million people.[19] A recent survey in Canada showed that 34% of Canadian seniors were at nutritional risk in 2008/2009. Women were more likely to be at risk than men.[20] Nutritional needs among other needs of older adults represent an important public health issue that should to be immediately addressed.

If children are hungry, they will certainly have tough problems in life: poor growth and education, poor future or early death. This is also a worldwide problem. We are facing two challenges. The first is related to overfeeding and physical inactivity associated with the classic cluster of non-communicable diseases in those who have a lot of choices of foods. The second is the worldwide malnutrition and shortened life expectancy experienced by many others who do not have these choices.

Although the challenge is enormous from both sides, there is still hope that this universal burden will not be forgotten and will continue to be tackled by governments, private partners, volunteers and organizations such as the Food and Agriculture Organization and the World Health Organization.

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2. The Contribution of Telemedicine to the Prevention and Treatment of Neurodegenerative Diseases

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I thank you for your invitation which I greatly appreciated. The request to speak about the role of telemedicine in the treatment and prevention of neurodegenerative diseases is connected with a problem that is of increasing contemporary relevance.

Indeed, these diseases afflict a large number of elderly people, a number that is continuing to increase. There are thus ever more patients to treat and care for in specialised institutions. This paper of mine links up with the concerns of His Holiness Pope Francis who has often spoken about helping people who are in need.

The work that I will describe to you is a result solely of my commitment, which I have adhered to since the beginning of my medical career, to providing access to quality care for everyone in every part of the national territory. Thus in 1968 I created the SAMU, starting with the CHC of Toulouse.

My goal was to provide, already at the site of a road accident, *access to the same medical and social treatment*.

The creation of the European Institute of Telemedicine in 1989, of the European Society of Telemedicine in 1991 and of the Midi-Pyrenees Regional Telemedicine Network GCS in 1998, enabled me *to build a team*, animated by *Dr. Monique Salvoldelli*, to promote and organise this new kind of medicine which is practised at a distance.

It is thus my intention in this paper to: 1. describe telemedicine to you from the beginnings of its activity in the field; 2. illustrate, through encouraging projects, its evolution and its determining role in the structuring of forms of cooperation; and 3. address the ethical points raised by this new medical practice.

1. A Description of Telemedicine

Telemedicine has developed in our country since 1996 and was defined as a *new distance practice* by the law of 13 August 2004 on health care and then by the law of 21 July 2009 on hospitals, patients, health and local areas.

Telemedicine is medical activity engaged in at a distance through an instrument that uses information and communications technology.

The various activities of telemedicine are defined by the French decree on telemedicine of 19 October 2010. These are as follows. 1. *Tele-consultation*, whose aim is to allow a medical professional to provide medical consultation to a patient. A health-care worker can be present at the side of the patient and assist, where this is needed, the medical personnel. During the course of such a tele-consultation psychologists can also be present where they are certain specific legal conditions of a social character. 2. *Tele-examination*, whose aim is to allow the medical personnel to request the advice of one or more medical professionals. 3. *Medical tele-surveillance*, whose aim is to allow medical professionals to engage in an interpretation at a distance of the data that are needed for the medical treatment of a patient and to take decisions relating to his or her treatment. 4. *Medical tele-assistance*, whose aim is to allow a medical professional to assist another medical professional during the course of the help he or she provides. And 5, the medical response engaged in within the framework of the SAMU.

Telemedicine is a new way of practising medicine within the context of the development of the health-care system, a factor that improves the quality of professional practice and the care and treatment provided to patients. It allows the implementation of a complementary use of professional skills and institutions so as to optimise the gamut of supply of care and treatment and of medical time to the advantage of patients. In this way are facilitated, on the one hand, the development of the organisation of the local-area supply, and, on the other, the use of highly specialised regional resources, in order to allow access to the level of expertise required and the most suitable treatment for patients in every part of the regional area, reconciling thereby topographical realities with therapeutic needs in the logic of managing the local area.

Telemedicine is developing throughout the world and in all fields of medicine. The variety and the quality of the work achieved by numerous countries, both inside and outside Europe, described within the framework of the European Society of Telemedicine of which I am the president, bears witness to this fact. Every year two scientific meetings are held.

However, in order to remain within the time allocated to my paper, I will limit the examples cited to work carried out in the region of the Midi-Pyrenees. I would like to observe that the region of Midi-Pyrenees, which is the region that I will talk about in this paper, is the largest in France, with a surface area of over 45,000 km2, which is more than Belgium, and 2,800,000 inhabitants. From April 1996 until December 2012 more than 42,000 individual dossiers of patients were addressed using telemedicine, with 38 disciplines and a constant growth which was especially marked in 2012, when over

10,000 individual dossiers were dealt with.

As regards the treatment of neurodegenerative pathologies, telemedicine brings surplus value to broaden the diagnosis, obtains more suitable treatment by facilitating access to therapeutic innovations, fosters prevention and limits the transfer of patients to proved cases. It makes possible a more frequent monitoring of a case, indeed as far as the home of the patient .

Work in this field in our region has been developed in particular in the treatment of plaque sclerosis and Alzheimer's disease.

As regards plaque sclerosis, monthly sessions of multi-site tele-examinations are organised which bring together the highly specialised service of the CHU of Toulouse and the principal hospital centres of the regional area. As regards treatment and care for elderly people with Alzheimer's disease, numerous projects have been developed, amongst which a gradual project involving Cognitive-Behavioural Units (CBU) and the Advanced Accommodation Units (AAU). Here we are dealing with regional multi-site multidisciplinary tele-examinations of the CBU in a pathway of coordination with a pole of geriatrics and tele-consultations at a local-area level between the AAU and their CBU of reference.

The aim is to foster a gradual treatment of grave behavioural disturbances in the CBU and treatment in the place of residence in an institution (AAU).

Telemedicine also allows an optimising of treatment and care for patients with Alzheimer's disease who live in residential institutions for dependent elderly people (EHPAD), with the prospect of an extension of this to 163 sites which will make up 38% of the institutions until the year 2017.

It is equally necessary to emphasise the relevance of this new practice as a vector for the ongoing and interactive training of the health-care professionals of the region. An analysis of the experience of our region and the expressions of the needs of professionals highlights the importance of allowing medical doctors near to hand to benefit from the tele-staff (interactive meetings for the coordination of distant teams) and constant tele-training sessions for specialised medical doctors, general doctors and all health-care workers provides an opportunity to meet simultaneously (using a multi-site), around a multidisciplinary team of reference that is distant in a geographical sense.

In our region we have counted more than 15,000 examples of participation by health-care professionals in tele-staff and tele-training organised over the last five years. This kind of use (tele-training, tele-staff) will continue. But it will increasingly be the needs connected with the care and treatment of patients that will be the engine that drives the development of telemedicine in the future.

Indeed, by now telemedicine is an integral part of the health-care pathway and is expanding the range of use of applications such as:

The personal medical dossier (PMD), which exists to integrate data and share information. This avoids an excess of examinations and allows a sharing of the health-care personalised plan (HPP) which provides information on the state of the patient and recommendations as regards social accompanying.

The OPR (Operational Repertoire of Resources), which allows users, professionals and the institutions of each local area to *find the pertinent effective service or person* at any moment of the pathway of healing. A general practitioner, observing that an elderly person can no longer carry out certain actions of daily life, seeks to find help to be provided at that person's home with reference to the name of a service, its address, supply, characteristics and availability.

The *'ViaTrajectoire'*, which is an ICT instrument for helping in directing and transferring hospitalised patients who request a continuation of their care and treatment in follow-up and rehabilitation services (SSR) or home hospitalisation (HAD). The idea is to extend this application to the field of handicap and to the care that is provided by clinics after a person is discharged from hospital.

The Messagerie Sécurisée de Santé (MSS), which allows the exchange of summarising documents such as reports or summarising medical work and to express the requests to the interested parties.

On the other hand, telemedicine is benefiting from the rapid development of mobile technologies (smartphone, tablet, medical sensors) and by high definition cellular phone networks (4G) and by now it enables patients to be cared for wherever they are within the framework of tele-consultation or tele-surveillance.

2. How is Telemedicine Evolving?

We can say like Jon Kabat-Zinn that 'the best way to take care of the future is to take care of the present. Now'.

Neurodegenerative diseases are caused by the death of neurons. The forms of treatment are essentially to do with the symptoms of these diseases. In addition to Alzheimer's disease, we may refer to Parkinson's disease and Charcot's disease, Creutzfeldt-Jakob disease, Huntington's chorea, etc. Only Parkinson's disease is treatable.

Faced with an increasing request for health care connected with the development of chronic diseases and polypathologies in a context of the ageing of the population, the model of near medicine, based upon the treatment of curable illnesses, is no longer adequate for constant health care.

New forms of organisation are necessary which involve cooperation between medical and paramedical health-care workers, between the health-care aspect and the medical-social aspect, so as to achieve overall and continuous care for patients with chronic diseases, whether at home, in EHPAD or in nursing homes.

In this context, 'success depends upon unity in diversity'. In some cases organisation and economic models have already been defined thanks to the help of Europe, by local government forces or by the state (the Regional Health-Care Agency).

I will explain here an initiative of the EHPAD in the High Pyrenees, a mountainous region where it is difficult for medical doctors to move around, above all when the weather is bad. For this reason nurses are very isolated. Thanks to European funds, GCS Télésanté Midi Pyrénées installed a connection through telemedicine with a medical office in the nearest town, that is to say Luz Saint Sauveur, which is linked to the hospital centre of Lourdes. Through telemedicine this unit can at the present time can take advantage of skills offered by those sites that can offer them in the region or outside it.

This situation has greatly changed the life of the EHPAD and contributed to the wellbeing and the growth of health-care workers and patients.

In the Department of the Midi-Pyrenees, GCS Télésanté Midi Pyrénées takes part, under the authority of the Regional Health-Care Agency, in the PAERPA project (Elderly People at Risk of Loss of Autonomy) whose objective is to strengthen cooperation and coordination between professionals of the health-care, social and medical-social sectors in order to minimise the lack of coverage, which is especially disadvantageous for certain elderly people, and to limit unjustified recourse to hospitalisation.

As regards funding, the PAERPA project envisages: conventional remuneration (article 45 of the Law on the Funding of Social Insurance for 2013); ONDAM (National Expenditure Goal for Health Insurance); and the Regional Intervention Fund (FIR). This arrangement seems to me to be very complicated because of the accounting systems that it involves.

We may also refer to a project for the identification of frailty. *Frailty is not an illness*. It is a predictive syndrome in relation to which it is possible to act in order to prevent dependency.

Prevention must be at the centre of 'accompanying and care for elderly people', to use the phrase employed by the French government. The Higher Authority for Health (HAS) has produced recommendations for the identification of frailty which are indispensable in knowing about the latest advances in the field of medicine for elderly people, dementias, disturbances of behaviour, nutrition, disturbances of movement and dependency, disturbances of the memory, the pathologies of residents in nursing homes and gerontological treatment.

The identification of frailty in the Pyrenees has been developed in Midi-Pyrenees within the context of experimentation engaged in by the SFGG (French Society for Geriatrics and Gerontology) and by the CMPG (National Congress of Professionals of Geriatrics).

The medical doctor of the case bases himself or herself on an identification table and can address, in the most problematic cases, the medical doctor of reference of the day hospital through tele-examination or tele-consultation in order to confirm the assessment and draw it up.

For these patients, where a decrease in movement activity is an important signal, an ascertaining of the implementation of prevention can take place near to hand, in a local multidisciplinary health-care centre, with the support of the basic paramedical personnel and the personnel of the day hospital, in relation to frailty in patients who are present thanks to telemedicine.

Lastly, I would like to refer to a regional initiative designed to produce and organise training courses to help 'those who help'. To this category belong people who care for the suffering, and this includes their family relatives. Thus the presence of non-health-care workers allows an alert to be sounded through telemedicine and often to deal with the situation. For that matter this is a form of action that is in line with the mission of His Holiness Pope Francis who has called for the mobilisation of everyone in order to help in all difficulties at a social and medical level.

In Midi-Pyrenees we have committed ourselves to this mission with the unconditional support of the local communities, within the framework of a university of one of our cities.

Beyond these projects, major questions exist as regards the organisational and financial forms of the spread of telemedicine on a vast scale. We still have to deal with structural questions although the technologies are mature and the framework of rules has been well established. Decisions can only be taken after a vast coordination of the interested parties. Only in this way, for that matter, will we witness the development of telemedicine at the service of our sick people.

3. Ethics

We may quote Albert Schweitzer: 'Each man should strive in the context in which he finds himself to bear witness to true humanity with others. The future of the world depends on this'.

The CNIL (National Commission for ICT and Freedom) decided to write this point in the programme of its directive on 'studies, innovation and promotion' as regards 'health, wellbeing in the world of numbers'. It has published advice on systems involving electronic treatment and care.

Although all of these methods meet a growing demand, we have to avoid them placing the rights and freedoms of individuals, and in particular their dignity, at risk. The consent of the individuals involved has to be obtained and where this is impossible the consent of their legal representatives or family relatives should be obtained, after they have been informed of the use of the method. Film cameras, when they are employed, should not be placed where respect for privacy is needed (bathrooms).

If the acceptability of instruments and services is conditioned by the optimisation of their integration with the software used by professionals in their daily practice, the request for technological 'transparency' should never lead to a concealing of the aspects connected with responsibility relating to the practice of telemedicine and, more in general, the exchange and sharing of health-care information. Learning about work in partnership in the context of cooperation relates at one and the same time both to institutions and to professionals.

In addition to the safety of the technology and systems that are used, one should also bear in mind the safety of the organisational processes. The foundations of cooperation rest upon respect for the identities and responsibilities of each person. The adoption of a code of good ethical and professional conduct must govern the use of partners in the field of telemedicine, at the service of cooperation. The duty to inform, to obtain the consent of the patient, to record exchanges and to protect the privacy of health-care data are important challenges in the relationship of trust with the patient within the framework of cooperative practices. In this area, the management of the entrusting of tasks and the recording of access to data are essential.

It is advisable to learn about the impact of the development of practices on the relationship between medical doctors and patients. The relationship of 'authority/trust' is replaced by that of 'quality/trust'.

Here there comes into play the juridical aspect which, in its turn, can trouble the professional relationships of the members of the health-care personnel, which by a snowball effect involves a deterioration in human relationships. The development of practices from the 'singular to the plural' and the rise of practices involving cooperation does not imply a dilution or an exemption but, rather, an accumulation of individual responsibilities as regards the agencies and professional involved towards patients, to whom, indeed, the best care is due. The hospital personnel must be fully involved, attend to possible hospitalisations and monitor transfers to urban doctors, both at an organisational level and at an operational and ethical level.

According to a phrase of Jon Kabat-Zinn, 'perhaps we should harmonise our vision just as we tune an instrument to increase its sensitivity, range and clarity'.

Our epoch is an epoch of the advent of numbers where entire parts of human existence are engaged in through processes of virtual communication: education and training, consumption, professional practice, the structuring of social and affective relationships, the practice of citizenship, access to culture, etc.

The role of the industrial sector (network workers, online services workers, ICT and electronic terminal technicians, etc.) has become of primary importance and obliges social institutions as a whole to revise their position.

Health and medicine do not escape this development. Telemedicine, inasmuch as it arose because of the fact itself of these numerical instruments and because it is by nature multidisciplinary and reticular, will become the new paradigm of medical practice. It will be the task of medical doctors, patients and their family relatives to adopt this new paradigm in a voluntary way in order to conserve its humanistic principles: respect for human dignity and care for the weakest.

We are in an epoch when the contribution of associations of sick people plays a high-quality role in providing information about, and organising, care and treatment. Patients, because of current advances as regards information, are encouraged to take part in the care and treatment that they receive. Telemedicine must be reflected in the context of these developments and to foster this role associations of patients come into being which in particular facilitate access to suitable medical skills and expertise.

Telemedicine will allow all patients to be assured good care and treatment and good accompanying, at the right moment, by good professionals who have available good information.

Innovation must be concentrated on the organisational form of medical practice. It must proceed by stages of experimentation in the field carried out by multidisciplinary teams (medical doctors, engineers, etc.)

I would like to make clear that an ambition can be achieved only by employing a method, that of listening and dialogue, which presupposes the involvement of all the interested parties.

We always have confidence as regards our objective because 'hope is the anchor of our lives. Who is the fool who would dare, without it, to set sail on this sea of our century, which is inhabited by winds and storms?' ■

3. Domotics and Robotics

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Introduction

The basic idea of ambient intelligence (AmI) described by Weiser[1] is still distant from becoming a reality even though in recent years many advances have been made. Research activity constantly offers new services and algorithms that are able to provide increasingly effective and sophisticated solutions. The *ubiquitous computing*, *ambient intelligence*[2] and *context-aware* paradigms hold up a picture of a future society where human beings will be surrounded, everywhere and at every moment, by intelligent interfaces incorporated into commonly used objects, such as intelligent furniture, clothes, vehicles, roads and materials. This vision envisages a high capacity connectedness by which people and objects are able to interact with each other and with the environment. A pre-condition for the achievement of such a vision is that the environment must in its turn be able to identify and locate users. In addition, the technological infrastructure must remain on the periphery of our awareness and move to the centre only if and when this necessary. Computational capacities thus become 'invisible'.

In such a vision, the home of the future will certainly be a technologically richer environment that will offer tens or even hundreds of services within a network that goes from the simple constant transmission of flows of video data to a complex system of managing the energy of the home. Some of these services will be provided by equipment within the home and others will be provided by external providers.

These services will allow everybody to manage a vast gamut of domestic home appliances and control the other vital functions of the home. In recent years attempts to improve the autonomy of elderly people, sick people and disabled people have begun to use technologies that are easily available. Environmental controls may be seen as useful aids in improving the functional capacities of many users. People with disabilities may be totally unable to make the objects that surround them function in a physical sense. Thus a domotic and robotic environment that can provide services that are just useful for the majority of users can, in the case of disabled users, become necessary in overcoming their physical limitations. The environmental system can be the only way by which these people can control the world that surrounds them. The typical elements within the home that can be controlled are: lighting, windows and blinds, loud speakers, heating, ventilation, air conditioning, electrical appliances (refrigerators, washing machines, ovens, etc.), audio-video equipment, burglar and fire alarms, and telecommunications.

Many sequences of operational control can be made automatic in order to avoid the user having to adapt to systems. Thus a major improvement in such control can come from the addition of a certain level of 'intelligence' to the system, thereby allowing it to recognise recurrent activities and dangerous or unusual situations in order to foresee health problems or the particular needs of users within the home. Such problems can be addressed through a monitoring of the activities of habitual users and this allows the creation of profiles based on rules in order to understand and formalise their normal behaviour. However, as regards privacy many people have problems when they learn that they activities are being monitored and this also relates to the way in which this takes place, what information is transmitted, and to whom. These concerns must obviously be addressed through appropriate agreements and the safeguarding of privacy.

Domotics

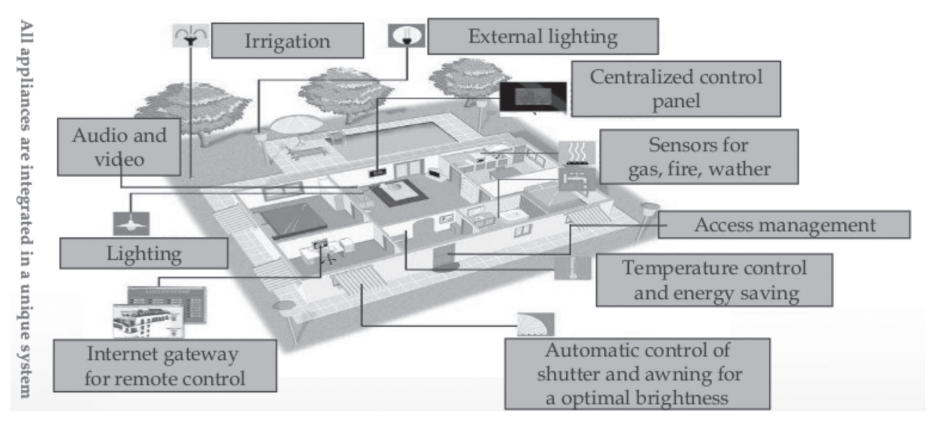
Domotics is the science that is concerned with the study of technologies that are designed to improve the quality of life at home and more in general in anthropised environments. This area, which is strongly interdisciplinary in character, requires the contribution of many technologies and professions, amongst which building engineering, energy engineering, automation, electrical technology, electronics, telecommunications, and information and communications technology.

Domotics allows the making available to users of appliances that go beyond the 'traditional' where equipment and systems are able to perform functions that are partly autonomous (according to reactions to environmental parameters that are fixed and pre-established), or programmed by the user or, but this has only recently been the case, completely autonomous (they act as reactions to environmental parameters and are activated by dynamic programmes). Through demotics it is possible to integrate various domestic users and functions, which have been traditionally distinct and separate, into a single cooperative and inter-operable network so as to be able to create dynamic functions that are increasingly advanced and intelligent.

In Figure 1 we can see examples of appliances and functions that can be inside a home. Thanks to a demotic appliance that is able to integrate and bring about the interaction of appliances, it is possible to created advanced and intelligent functions which it would otherwise be difficult to produce or which would be highly complex, such as for example:

– An irrigation system that is controlled by the weather station: the irrigation is turned on only if it is not raining or has not rained recently.

Figure 1. Examples of domestic appliances and functions



– The outside lights are controlled by the weather station and by a presence sensor: the lights are turned on if the weather station sees that it is dark and if the sensor detects a person passing by. After a certain period of time, the lights are turned off autonomously.

– A single touch screen that allows a control of the various appliances in the home such as awnings and blinds, lights, the principal electric appliances, heat regulation etc., using a single interface (Figure 2).

– Water and gas supply valves that are controlled by sensors that detect leaks: when a water or gas leak is detected the relative valve is closed so as to avoid damage or dangerous situations for those who live in the home.

– The regulation of heat controlled by sensors: the sensors allow the activation or deactivation of radiators or air conditioners only in environments that are being used.

– Awnings and shutters are activated by the weather station and by light sensors: awnings and shutters are than placed in relation to the position of the sun, the weather situation and the light inside the environment, in order to achieve an optimal lighting of those living in the home.

– The internal lights are controlled by a light and presence sensor: if not enough light comes in and if the presence of people in the environment is detected, the lights are automatically switched on and then turned off when there is no longer anyone there.

Figure 2. A domotic touch screen

– Enabling or temporary preventing access to the home by people (for example by a fingerprint reader or a video camera that recognise faces) in relation to the typology of people and times of the day. For example, the cleaning women can enter only between 8.00 and 9.30 in the morning, the children can always come in, etc.

– Managing electricity flows and temporarily turning off electrical appliances when an excess of consumption in the same period of time takes place in order to avoid a black out. For example, if the electric oven and the washing machine are turned on at the same time when there is more than 3kW/h, it is possible to turn off the washing machine until the cooker has completed its task, or it is possible to posit the use of electric appliances in relation to the consumption rates, for example if both the electric oven and the washing machine have to be turned on, the system can turn on the electric oven when the washing machine is engaging in low consumption of electricity and this lasts for a sufficient time for the oven to complete its task.

– Managing electricity flows by activating them where there is a production of energy from renewable sources or at specific times of the day. For example, it is possible to turn on electric appliances which are high consumers of electricity, such as for example boilers, washing machines etc, only when it is possible to use energy produced by panels, wind systems, etc.

– Managing domestic appliances at a distance: a demotic system is completed, usually, through one or more systems of communication with the external world, such as, for example, pre-recorded telephone messages, SMS, the automatic production of web pages or e-mails, in order to allow a control and visualisation of the state of the appliance, from far away as well.

In general, domotics offers mechanisms which aim at:

– Comfort: to make the life of the inhabitants easier and more comfortable by managing certain environmental parameters such as temperature, lighting, etc.

– Energy savings: an automatic management can allow significant energy savings. For example, it is possible to automatically turn on electrical appliances that have a very high energy consumption only at specific moments during the day or in certain conditions, such as the possible self-production of clean energy through panels or wind systems.

– Safety: the safety of a person within a domestic environment, such as for example a system for controlling falls, certain vital parameters, etc. Safety is an especially important factor for disabled people, the elderly and the chronically ill, because for them it means being able to have more autonomy.

– Security: such as anti-intruder systems.

– Remote control: being able to control and command the house from afar.

– Entertainment: managing multimedia systems such as audio or video equipment.

– Access to external services: acceding to services provided by third parties such as those which allow taking part, from home, in socio-political life (e-government), socialisation and social inclusion, contact with relatives, friends, etc.

– Integration of all the domestic appliances: in order to create a single network that includes all the appliances in the home in order to be able to achieve and manage advanced functional capacities.

Thanks to the integration of domestic appliances, demotics allows the use of the same equipment for more than one task on the basis of the contingent situation.

For example, a presence sensor (Figure 3) can act as an alarm system when nobody is at home and to turn on and turn off lights when people are in the home. The magnetic contacts placed on doors and windows (Figure 3) can be used as anti-intruder systems when nobody is at home and to temporarily turn off the heating regulation system when a window is opened.

Assistance Demotics

Assistance demotics is that branch of demotics which seeks to help elderly people, the chronically ill and the disabled to stay in their homes in complete safety and comfort. A made to measure home for these people allows them to compensate for the physical or mental limitations of their states of health, thereby increasing their quality of life.

Examples of assistive demotics are:

– The control of the domestic environment using the voice, thoughts or gestures. A person can, for example, open the front door of the home from any place in the environment or physical position (for example a bed).

– The integration of medical equipment with domotic appliances such as, for example, the use of a pill dispenser which automatically provides medical products on the basis of the state of health of the patient.

– The guaranteeing of greater personal security through, for example: a system for monitoring falls, the use of visual and sound alarms.

– The use of telecommunications platforms so as to ensure that the patient does not feel lonely, keeping him or her in contact with his or her family and friends and making him or her actively participate in social life although he or she remains at home.

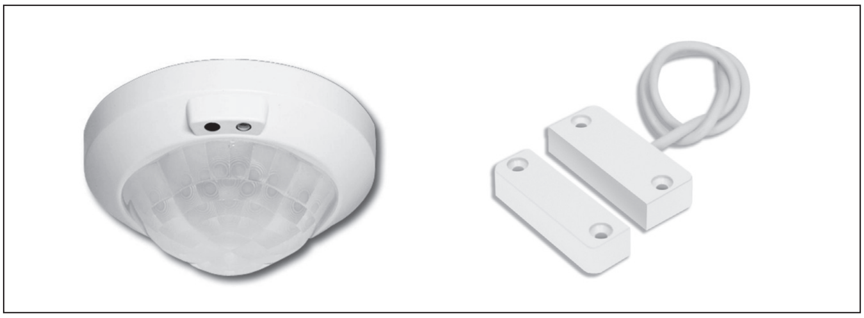
– The use of serious games in order to maintain the patient's mind active and to periodically test his or her psycho-physical state.

– The monitoring of the activities of patients who have reduced cognitive capacities, impeding them, for example, from leaving their homes not subject to vigilance.

Robotics

Robotics is a branch of technology that concerns the planning, the construction, the activity and the application of robots When we usually think of a robot we imagine something with a human appearance that is able to cooperate like a human being. Unfortunately, technology is still very far from managing to create a robot that is able, for example, to place clothes inside a washing machine, to iron or to dust (Figure 5).

Figure 3. Presence sensor and magnetic contact



One goal of robotics is to develop humanoids that are able to learn, to cooperate and to become peaceful and friendly partners for human beings.

A humanoid is a robot that has the same general structure as a human. Like a human, it walks on two legs, has a torso, two arms, two legs and a head. A humanoid does not necessarily resemble a real person in a convincing way. For example, the ASIMO humanoid[3] has a helmet instead of a face. (Figure 6).

In contrary fashion, an android (male) or gynoid (female) is a humanoid designed to resemble a real person as much as possible, for example, iCub[4] (Figure 7).

A cyborg, on the other hand, is a robot built out of biological parts and artificial parts.

Figure 4. Instrument used in assistive domotics

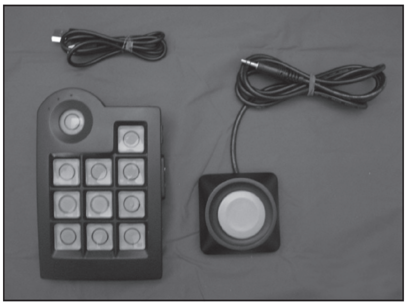
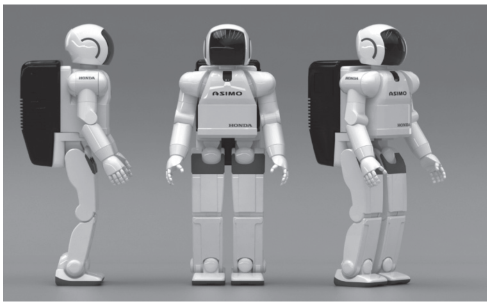


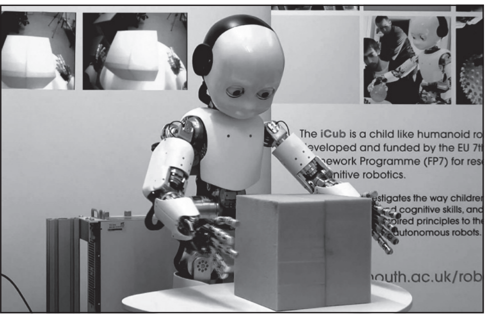
Figure 5. From the film 'Io e Caterina', directed by Alberto Sordi, 1980.

Figure 6. The ASIMO humanoid



In the world of research a humanoid is a robot the study of which is especially interesting. It is an ideal model by which to achieve the hopes outlined above. In order to understand the reason for this one must start from an assumption: a human carries out a series of actions on the basis of the experience that he or she has acquired in a direct way (trying, making mistakes, etc.) and an indirect way (by teaching and/or looking at other people). For example, to open the door it is noticed that the handle has to be pulled down and to do this a specific hand and arm movement has to be engaged in, with the door then being pushed. When a human has to open a door, he or she knows by experience that these actions have to be carried out, without raising problems about how the handle works, why it turns and above all the physical laws that are involved (the forc-

Figure 7. The iCub android



es at work) which act during this manoeuvre. This demonstrates how experience is at the basis of intuition and how a human interacts with his or her environment.

Having similar physical structures helps a humanoid to acquire experiences similar to human experiences. In this way is fostered the process of man-robot learning, exploiting the universal language of communication – body language. To learn from human experience, a humanoid has to be equipped with self-learning systems which allow it to increase experience through interaction with the environment and with people.

Ambient Intelligence and Internet of Things

Ambient intelligence (AmI) is a paradigm that seeks to achieve intelligent environments where people can live surrounded by ICT and television technologies. In order to respect the basic principles of this paradigm, the technologies that are used must be:

– Immersed: integrated into the environment and invisible to the user.

– Inter-operable: all the appliances must be able to communicate with each other independently of their technology, brand, model, etc.

– Aware: able to recognise the user and the environmental context in which they are applied.

– Personalised: made to measure to meet the specific needs of each person who uses them.

– Adaptive: able to change and shape themselves over time in relation to the new needs and requirements of the people who use them.

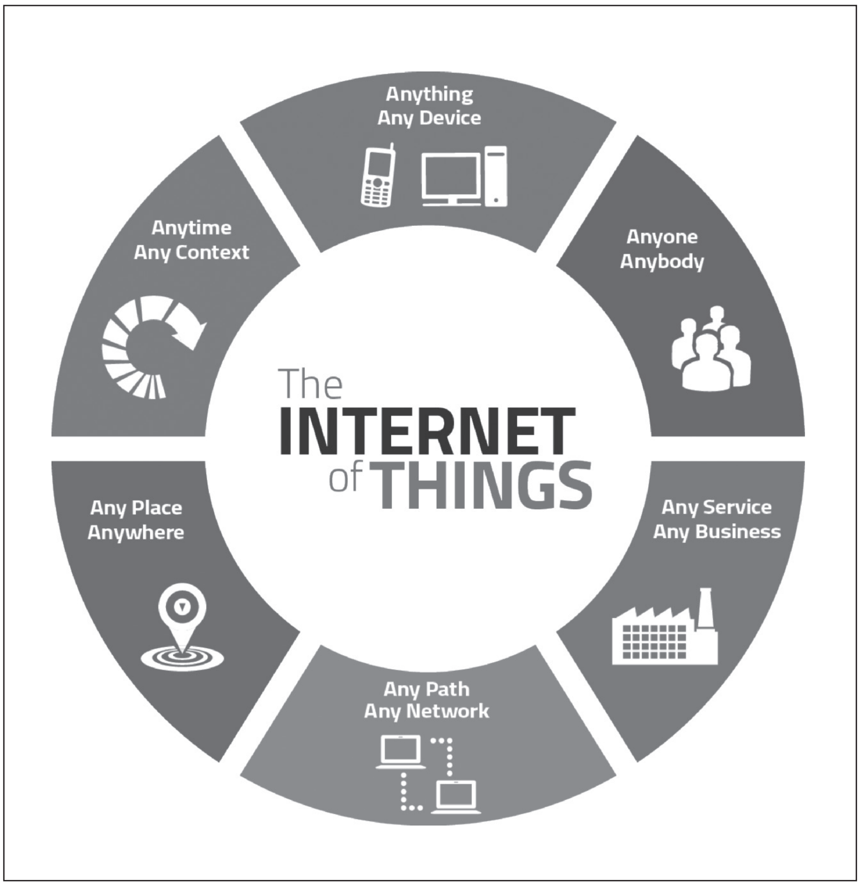
– Predictive: able to predict and meet the needs and wishes of the people who use them before these people perceive the need for this.

Internet of Things (IoT) is a paradigm that refers to the fact of being able to identify univocally an object or its virtual portrayal within an internet network, where objects become recognisable, acquire intelligence, and are able to communicate data to each other and to accede to the information of other appliances. All the objects connected with Internet of Things have a pro-active role in connecting with the Net (Figure 8).

Applied examples of Ambient intelligence and Internet of Things are, for example, an alarm clock that goes off at a time that varies according to the level of traffic on the roads; shoes in a corridor which are able to transmit immediately to people who are elsewhere the chronometer readings, speed levels and distance walked, perhaps allowing people to compete together; and the pill box of the patient which alerts his or her family relatives if the medicine has not been taken. Other examples of applications that can change daily life are: lighting, temperature and music which are adapted automatically to the psycho-physical state of the people living in the home, without the need to dial numbers or push buttons; pictures whose contents change according to the mood of people or walls that change colour on the basis of levels of anxiety; and a home that perceives emotions and stress, detecting facial expressions, posture or physiological parameters (such as breathing rates, heart beats or body temperature) through appliances that can be worn or bracelets with suitable sensors (such as the *eye-tracking* and *webcam* systems).

Domotics and robotics have similar problems and solutions. These two technologies can cooperate together in order to improve the functions of a home and offer increasingly advanced systems, in

Figure 8. Internet of Things: everything is connected to the Net



particular for elderly people, disabled people and the chronically ill[5].

To attain thee goals both domotics and robotics need to solve certain problems and these include: (Figure 9):

A semantic context: contextualising the environment and the user. These technologies have to know and understand the environment and the user in a total way.

Techniques of artificial intelligence: to acquire knowledge and know how to use it.

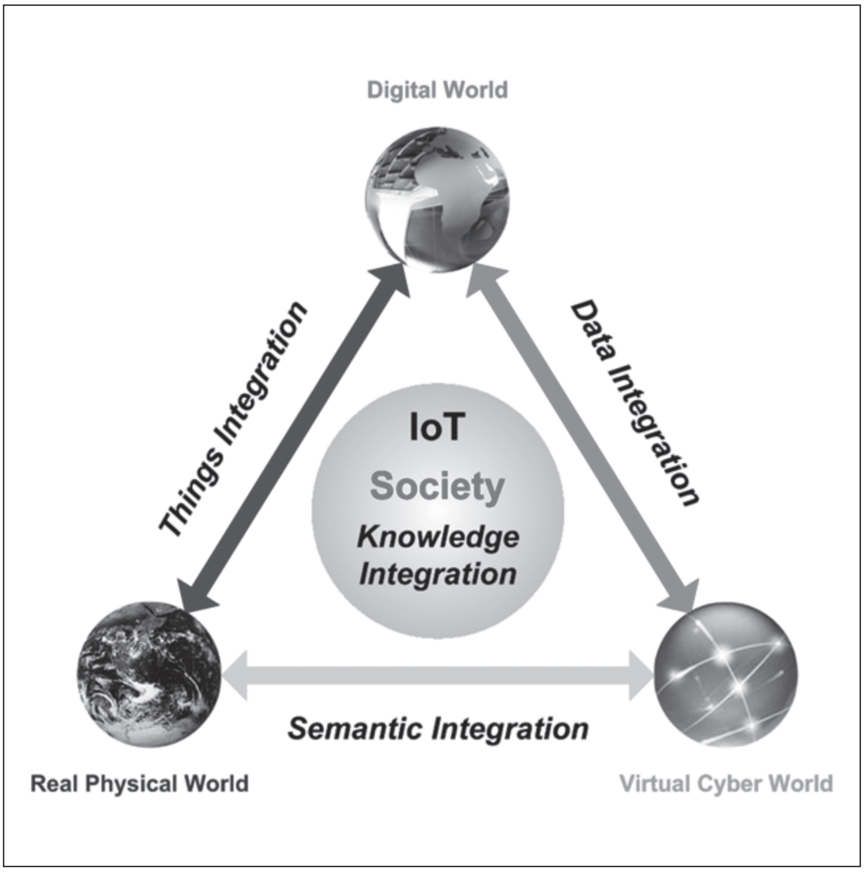
The CNR and the Laboratory of Domotics

The CNR (National Research Council) is the largest state agency for scientific research in Italy. The mission of the CNR is summed up in the goal of creating value through the knowledge generated by research, pursuing, through the development of scientific research and the promotion of innovation, the competitiveness of the productive system, and meeting the individual and collective needs of citizens. On the basis of this mission, there is the belief that research and development activity is of determining importance in generating greater employment, wellbeing and social cohesion.

The scientific network of the CNR is made up of over a hundred institutes that are organised and present throughout the national territory of Italy and it is a network that is characterised by a high level of multi-disciplinary approaches which mark it our from all other agencies in Italy. Thanks to its capillary structure in the national territory of Italy, the CNR promotes a vast dissemination of its roles and capacities, facilitating contacts and cooperation with local companies and organisations.

The ISTI (Institute of Information Science and Technology) is an institute of the CNR and is located in the research area of the CNR in Pisa.

Figure 9. Elements of AmI and IoT



The mission of the ISTI is to generate scientific excellence and play an active role in the transfer of technology. It is organised into five subject areas: the science and technology of networks; the science and technology of software; the technologies of knowledge; visual and high service technologies; and flight and mechanical structures.

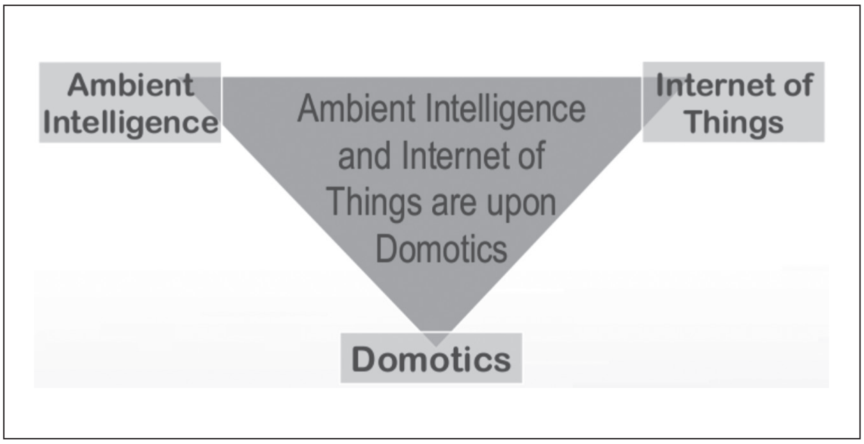
The Laboratory of Demotics is structured inside the ISTI and focuses its research activity in order to contribute to the creation of new domestic-environmental scenarios in which computational capacities are not confined to traditional calculating appliances but are also extended to ordinary things. Objects and the environment will interact with each other in order to support users in the carrying out of daily activities in a natural way, using the information and the intelligence that are concealed in the domotic network that connects the appliances together (technological complexity will become invisible for the user).

Starting with state of the art domotics (Figure 10), the laboratory engages in research activity in the sectors of ambient intelligence and internet of things, concentrating on three fundamental paradigms: ubiquitous computing, ubiquitous communication, and friendly intelligent interfaces. Its efforts are directed towards the creation of a cyberspace that is not deterministic and is open, within which autonomous and intelligent entities interact so as to place man at the centre of a design that will achieve the completely integrated creation of the home of the future. This space will be able to organise itself and adapt itself, fitting itself to the user and predicting his or her needs.

To meet these challenges, the laboratory works in a domain that is necessarily interdisciplinary in character, which includes ICT science, the social sciences, electric and electronic engineering, industrial design, architecture, and the cognitive sciences.

The operational fields extend to the ‘smart cities’ level with the automatic and non-invasive integration of various AmI environ-

Figure 10. Domotics as a basis for AmI and IoT constructions



ments (such as the home, cars, public spaces etc.), envisaging, in addition, that special attention will be paid to the needs of elderly people, the supervising of children, the problems of disability and safety, telemedicine, e-government and e-democracy.

The laboratory is a member of the KNX European association, KNX Italy and the UPnP association.

New Approaches for Elderly people, Sick People and Disabled People that have been Conceived and Created by the Laboratory of Domotics

Thanks to the technological progress that has led to the miniaturisation of electronic components, to scientific research that is finding new solutions in fields relating to ambient intelligence and Internet of Things, most objects of daily use have become by now increasingly technologically advanced, evolved and functional. This trend is constantly intensifying and in the short term it will certainly be possible to create a myriad of developed applications which have hitherto been unthinkable. Whereas hitherto the user has had to adapt to the constraints and limitations of technology, the goal of the Laboratory of Demotics is to ensure that in the near future both technology and the surrounding environment will have to adapt to the needs and requirements of people and not the other way around. The vision of the laboratory is to place man at the centre of attention and to make him an active and principal agent.

Motivations

Hitherto the approaches that have contributed in an important and significant way to the management of the heath of elderly people, disabled people and the chronically ill, inside their homes, are to be looked for in the field of telemedicine. Indeed, these systems allow patients to be monitored constantly and at the same time allow them to live their lives inside their own homes in full safety and security. The medical appliances for the constant control of vital parameters, for example ones that are placed inside jerseys, bracelets, watches etc,, are increasingly sophisticated and increasingly allow accurate and careful control in order to identify and then suitably point out situations of danger where intervention is required.

Often, however, between the moment of the call (even if it is automatic) and the actual intervention, an emergency is already underway and unfortunately it can have dramatic effects. A system that is able to predict a danger before it presents itself could allow a more rapid and effective intervention which could make all the difference and often save lives.

The solution studied and made into a prototype by the Laboratory of Demotics is a software system that is able to go beyond the current limitations of telemedicine by introducing assistive and innovative software technologies that are able to:

– Contextualise the environment and the users, enriching the system of semantic systems in order to:

- Be able to identify an appliance using its description and/or characteristics, such as, for example, ‘lamp on the bedside table’, ‘the television in the kitchen’, etc.
- Provide an objective to the system without specifying how to achieve it, which then autonomously finds the best pathway for this, such as, for example,: an indication to ‘have more light in the room’ allows the system to understand autonomously whether it is appropriate to turn on a light and/or raise blinds and/or an awning, seeking also to maximise energy saving.

– Apply techniques of machine learning to learn the habits and preferences of patients. This allows:

- A prediction of the actions of the users on the basis of their previous activities. In learning the habits of people, the system is able to predict events at the most opportune moment such as, for example: returning home, turning on the light in the living room, turning on the radio and raising the blinds.
- A monitoring of anomalous forms of behaviour on the part of the user. If a form of behaviour is unusual, it could be a sign of a physical malaise or a state of mental alteration which could be pointed out immediately to those who should know about it. Some signals, such as, for example, a long sleep on the sofa, significantly longer time taken to go up the stairs, etc., could be symptoms of a possible worsening of the illness in the patient.
- An adaption of the rules that have been learnt to changes in the habits of the user. In certain circumstances the patient can change his or her habits and the system must be able to learn them and change the previous rules, for example: in spring the patient leaves home more frequently than during other seasons of the year.

The laboratory has a gallery

**Figure 11.
The laboratory gallery**

(Figure 11) which is open to the public and which describes certain solutions that were studied and created within the framework of its research activity.

Conclusions

Loading dish washing machines and clothes washing machines, dusting and ironing, are still today activities that have to be done manually despite the fact that advances in technology will allow a revolutionising both of domestic work and of life as we now know it. In a particular way, technologies that involve assistive methods, safety, prevention and comfort, are advancing every day and offering increasingly effective systems.

Many of the possibilities described above are at the research and development stage and a great deal of work still has to be done, above all in the field of scientific research. Some systems are already available, as in the case of domotics, which are already able to offer support instruments, which are currently at varying levels of development, for numerous situations.

The system developed by the Laboratory of Domotics, using techniques of artificial intelligence, is able to automatically activate actions identified as being repetitive, such as, for example, turning off the lights when the television is on; automatically turning on the alarm system shortly after the television and the lights of the home have been turned off; and automatically lowering the volume of the television when the telephone is about to ring. In the same way, in the laboratory studies are underway so that a system that is based on the same ICT principles will manage to prevent possible health emergencies, recognising in a personalised way changes in routine activity, detecting protracted anomalies, for example coughing or the frequent use of the bathroom, and possibly being able to inform the patient's medical doctor or family relatives. These innovations are being applied to the field of care for the elderly, the sick and the disabled.

The Laboratory of Demotics has expertise in the sectors of domotics, ambient intelligence and ambient assisted living, including the development of software in these sectors (desktops, the Web and mobile appliances). It cooperates actively with various universities and Italian and foreign companies and various institutes of the CNR. The laboratory is open to proposals to cooperate in the drawing up of proposals for technological and research projects to be subjected to public tenders and to engage in research, consultancy and transfer activities with third parties for companies.

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SEVENTH SESSION

THE THEOLOGICAL AND PASTORAL PERSPECTIVE

1. Aging of the Person and the Spiritual Meaning of Life

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When I was a medical student, I remember being on the wards and seeing the ill older patients alone in their rooms. Various reasons were given – they need quiet and rest, "I am very busy right now with people who really need me", "I'll be right there" – yet I would see the residents, nurses, and others continue in the business of the wards. The older persons just lay there unattended. When I went in to see the patients, sometimes they would just look up with a vacant stare in their eyes – "Dementia," one resident said, "no one is there anymore." Sometimes I met an angry person – "Get out of here. I can manage this myself." Another time the person was just sobbing, unable to describe what it felt to be in deep suffering and pain. And many times, they would just look up with tears welling up in their eyes, only too happy to have someone sit next to their bed, listen to them, hold their hand, or just show genuine care and interest.

What I witnessed was true suffering, suffering that can be due to a person's sense of independence and dignity being threatened. The angry person I met may have had this type of suffering – fighting hard to maintain his dignity and independence. Activity limiting conditions such as memory impairment, arthritis, advanced and complex illness, can all result in increased dependence on care from others. As resources for that care are expended, people can start to experience financial strain that only exacerbates the suffering.

Aging also involves the experience of loss. A family member or friends can die, leaving a person alone and empty. People can question the fairness of having to bear such pain and sense of absence of God.

Suffering

Suffering can be defined in many ways.[1] Definitions are many: the presence of inner distress, lack of meaning or purpose, grief/loss, hopelessness, worry, and isolation. Wright describes several experiences of suffering, including the alteration of one's life and relationships with serious illness; the forced exclusion from everyday life, the strain of trying to endure; the longing to love or be loved; enduring acute or chronic pain; and experiencing conflict, anguish, or interference with love in relationships.[2] Issues of forgiveness or reconciliation may play a dominant role in the older person as they review their life and uncover issues for which they need to be forgiven or in the recognition that they are harboring resentment they need to release by forgiving another who may have hurt them. Suffering can threaten the intactness of the person[3].

In the midst of this suffering, it is not uncommon for people to question God, fairness, and life choices. People often undergo a life review, where issues related to their life, relationships, and self-worth might arise. All these issues can provoke deep suffering, which can result in people feeling hopeless, alienated from themselves, others, God, or from their ultimate source of meaning or love.

Suffering may also be manifested as physical pain, depression or anxiety, social isolation, and spiritual or existential distress. However, pain is multidimensional and may be exacerbated or relieved by attention to the other dimensions of suffering. For instance, spiritual or existential distress can exacerbate the presentation of other symptoms such as pain, agitation, anxiety, and depression. Some studies suggest that existential and spiritual issues may be of greater concern to patients than pain and physical symptoms.[4,5] Thus, when patients talk of pain, they may be referring to pain in one of any of these dimensions but are using clinical words to address it. Unless the clinician is attentive to all the dimensions of suffering – the psychosocial and spiritual, as well as the physical – the entire focus may be on physical pain and not address the spiritual or existential distress or suffering.

Not addressing spiritual or existential suffering can result in perhaps the greatest of suffering. In the hospital, I experience the tragedy of today's healthcare system and society's discomfort with the witnessing of suffering. Usually, The cause of this discomfort is a sense of deep pain and a recognition that the suffering of the other cannot be fixed. This causes perhaps the greatest suffering to the patients – the awareness and feeling of being unloved or unconnected. Seneca wrote of a dying person who pleads, "Please listen to me for a day, a moment, lest I die in my lonely wilderness" (Lucius Annaeus Seneca (4 BC–65 AD).

Spirituality in the Care of the Suffering

There is a significant body of literature that highlights the role of spirituality in aging. As we age, spirituality plays a more dominant role in our lives than when we were younger. The finitude of life on earth becomes more obvious as we age, and the questions about meaning, purpose, and connection become more critical for us. In 2009, a national consensus conference was held to develop models and recommendations for how spirituality can be integrated into the clinical care. The invited attendees, representing a diverse group, agreed on a common definition of spirituality, which is broad and encompasses religious, secular, humanistic, philosophical, and other expressions of sources of deep meaning for people. This definition is:

"Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose, and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred."[6]

Spirituality as a search for meaning and purpose implies an ongoing life long process. Meaning can be understood a meaning with a small 'm' which refers to activities, relationships, and values that are meaningful to a person but don't define the ultimate purpose of that person's life. Meaning with a capital 'M' refers to values, beliefs, practices, relationships, experiences, that lead one to the awareness of God/divine/transcendence and a sense of ultimate value and purpose in life. Throughout ones life the person moves between the 'm' to the 'M.' Triggers for this movement include illness, loss, life stress, societal tragedies, and chronic or life limiting conditions, including aging.

Every individual has to make a decision as to whether one's life has both meaning and value that extend beyond self, life, and death. Dealing with these existential questions focuses on a relationship with a transcendent being or concept.[7] Spiritual and/or religious beliefs have been shown to have an impact on how people cope with serious illness and life stresses. Spiritual practices can foster coping resources, sense of coherence and meaning in patients as well as family caregivers,[8,9,10,11] enhance a sense of well being and improve quality of life,[12] increase one's will to live,[13] provide social support[14] and generate feelings of love and forgiveness.[15] Spiritual beliefs can also impact healthcare decision-making.[16] Numerous surveys have indicated that people turn to spiritual and/or religious beliefs in times of stress and difficulty. Interestingly spirituality can also improve pain management,[17] which is not surprising because distress is likely multifactorial, with psychosocial and spiritual causes of pain and suffering as well as the physical. Finally, spirituality may help people have more realistic sources of hope, meaning in life, reconciliation, and hope for finishing important goals. Spirituality helps reframe the trajectory of illness and aging from a purely cure-oriented one to one of healing and inner peace.

Gerotranscendence

Gerotranscendence is a relatively new term, used to describe the developmental spiritual stage associated with older age. Aging persons shift from a materialistic and rational vision to a more cosmic and transcendent one. Thus in the stage of gerotranscendence people begin to detach from those parts of their life – such as job titles, financial success and buying more things, and some can also detach from illness or debility – in favor of a more focused attention on those things that matter most, on legacy building and mentorship, and on relationships. In Ku Luven researchers developed a Gerotranscendence scale to study this stage in greater depth.[18] They found three subscales – transcendent connection, anxiety and uncertainty, and active involvement. In transcendent connection they found that spiritual views and practices positively correlated with transcendent connection; anxiety and uncertainty about death is lower in patients with strong spiritual and religious beliefs. Finally, the researchers found that in terms of active involvement, people in the Gerotranscendent stage people have an increased need for solitude; they tend to rejoicing in small events, and live a life some describe as modern asceticism. Interestingly these latter behaviors were seen as negative by nursing home staff as signs of depression. This just points out how critical it is to be able to distinguish depression from normal contemplative aging.

The improved coping in people with strong spirituality as describe above probably has to do with their ability with reframing. Attention to the spiritual dimension can help the older person reframe what may seem like a limited phase of life to one that is expansive and full of opportunity for inner growth and for contributing to the next generations.

John of the Cross, a 16th century mystic describes this reframing when he wrote "Live as though only God and yourself were in this world, so that your heart may not be detained by anything human."[19] Aging or awareness of our mortality sharpens our focus on what matters most.

Compassion: An Antidote to Suffering

While suffering cannot be fixed, relief from suffering can come from compassionate connections that healthcare professionals form with their patients. The Dalai Lama wrote a forward to the book entitled, *A Time for Listening and Caring: Spirituality and Care of the Chronically Ill and Dying*.

"When people are overwhelmed by illness, we must give them physical relief, but it is equally important to encourage the spirit through a constant show of love and compassion. It is shameful how often we fail to see that what people desperately require is human affection. Deprived of human warmth and a sense of value, other forms of treatment prove less effective. Real care of the sick does not begin with costly procedures, but with the simple gifts of affection, love, and concern." [20]

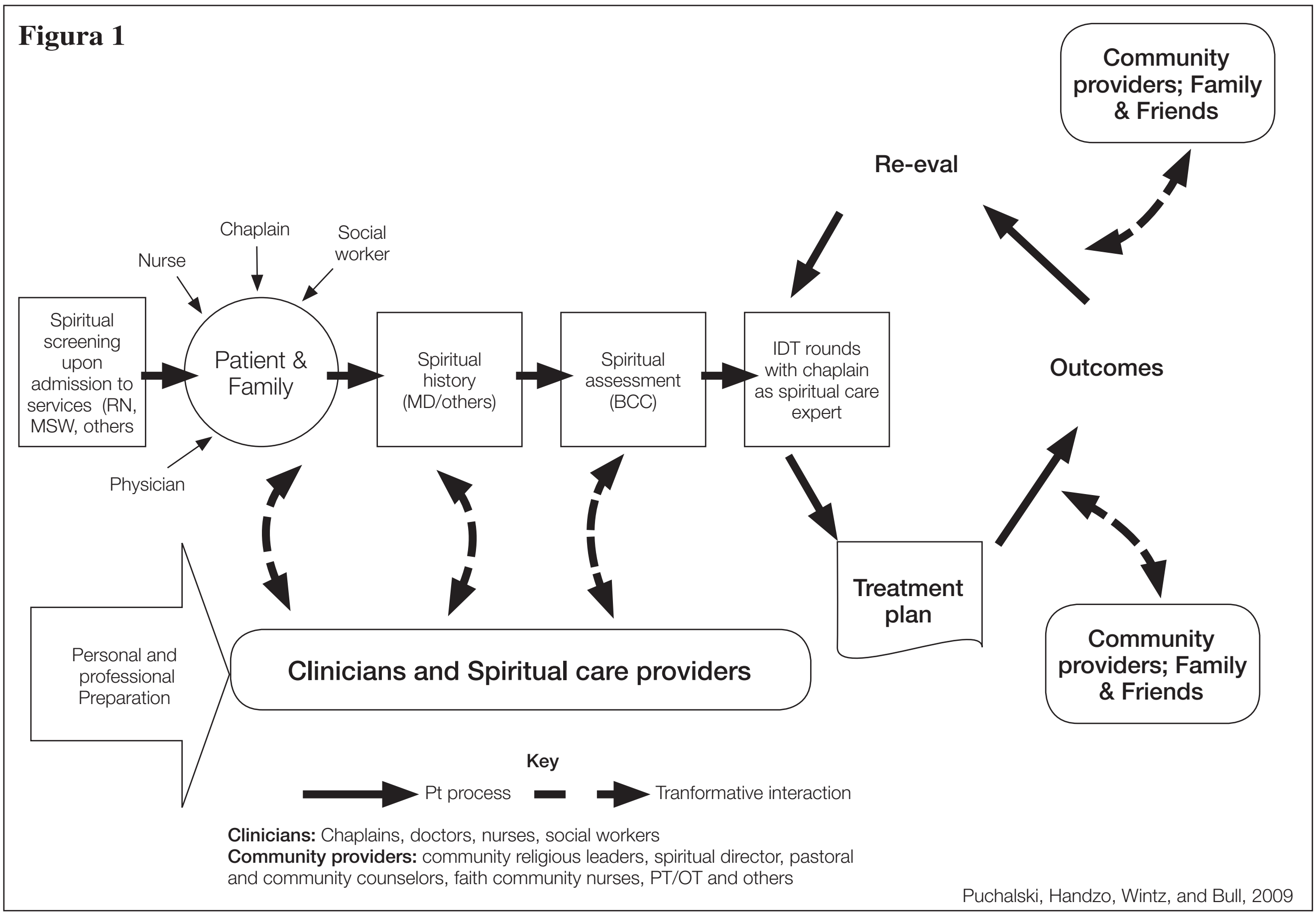
Compassion is an outgrowth of inner spirituality.[21] In order to better help those who are suffering, much work has been done to integrate spirituality into healthcare. In addition to the 2009 National Consensus Conference described above, two more consensus conferences were held in 2012 and 2103 – one in the US and one in Geneva, Switzerland.[22] All these conferences concluded that spirituality, broadly defined, enables clinicians and others to be fully present and loving with their patients.

Guidelines and models from the above conferences described an interprofessional model of spiritual care. This model is integral to any patient-centered healthcare system, its based on honoring dignity, attending to suffering. In this model spiritual distress should be treated as any other medical model. It should be interdisciplinary with trained chaplains as the spiritual care experts. Clinicians should do a spiritual screening or history and patients' spiritual issues; their suffering must be integrated into the whole person treatment plan.[23]

The model (figure 1) simply shows the trajectory of a patient and their family in the clinical setting. Patients receive a spiritual screening upon admission to the hospital to see if the patient is in spiritual distress and needs an urgent chaplain referral. They then have a spiritual history as part of the routine clinical history. The spiritual issues of the patient are integrated into a treatment plan. Clinicians refer to chaplains to help treat spiritual distress or suffering. Chaplains do a more extensive spiritual assessment in which they listen to spiritual themes and develop a plan of care, with outcomes and follow-up. Then chaplains communicate with the rest of the team. Community providers include family, friends, clergy, and culturally based healers.

This model is created to make spirituality more accessible. While reductionist, the model is also holistic. It is dignity focused, with the core values of each individual being respected. It depicts care as coming from a community

Figura 1



Clinicians: Chaplains, doctors, nurses, social workers
Community providers: community religious leaders, spiritual director, pastoral and community counselors, faith community nurses, PT/OT and others

Puchalski, Handzo, Wintz, and Bull, 2009 that includes the patient, family, healthcare workers, spiritual care professionals, and religious leaders. It is practical and designed to fit within the medical model so that suffering is not neglected but is treated as any other distress. A typical whole person treatment plan is described in Figure 2.

Figure 2. Whole Person Assessment and Treatment Plan

A 65-year-old patient admitted for repair of hip fracture; surgery went well, without complications, also noted anxiety, separation from religious community. Has strong spiritual beliefs, good level of hope, strong family support. Spiritual goal includes deepening relationship with God. Expressed interest in learning meditation.	
Physical	s/p ORIF for PT/OT
Emotional	Anxious about not being able to work; has panic attacks at night. Continue with alprazolam qhs; referral for counseling with social worker at rehab
Social	Encourage family to visit at rehab
Spiritual	Isolation from church community; goal to deepen relationship with God. Referral to chaplain at rehab; referral for spiritual director once discharged from rehab; also gave list of meditation centers and teachers in patient's community

Being a Witness to Suffering

In figure 1 above, the dotted line refers to the transformational relationship between the patient and the clinicians. The professional caregiver is changed in the relationship, as is the patient. This potential for transformation will only occur if the clinician can be open to that relationship, open to being changed by another. Because a relationship with one who suffers can raise issue for these professional caregivers, the clinicians, chaplains and clergy need to focus on their inner or spiritual and emotional development to be able to do the clinical work. Until we have an awareness of our inner call to serve and until we develop the inner resources to deal with the suffering of the other, we will not be able to stand in witness to that suffering.

Ministry to patients and/or parishioners is stressful. We engage in deep relationships with patients and staff. Our patients' suffering brings up issues for us. Thus we need to examine what theses issues are as they arise. We need to be reflective practitioners, always examining our interaction with our patients or the people we serve, and how those interactions affect us and perhaps transform us.

Self-care is also critical to our capacity to be compassionate. The core principle of altruism makes it hard for clinicians and clergy to care for themselves. Having a spiritual practice is essential; taking care of our health and physical as well as emotional wellbeing is also absolutely needed. Making sure we have social and other supports can enable us to find the strength to be fully present to another person and in full service to the other.

As demonstrated in the opening stories of patients in a busy hospital setting, clinicians can make legitimate excuses to avoid the suffering of others. Clergy also have to deal with these same issues. One clergy colleague told me that at times it's easier to administer the sacraments than to sit and be presence to the deep suffering of another. The natural tendency we all have to fix pain does not work for suffering. The person who can witness to it but not attempt to fix it can attend to suffering. Witnessing the suffering of another gives a voice to the person who suffers. When that person is truly heard in the silence of deep compassion and love, he or she may be able to find a path of healing within themselves as they cry our in their pain, in their sense of hopelessness and despair, and in their deep longing for connection and peace. It is in being a witness that we can offer the person the strength to find that healing within themselves and to connect to what they see as the significant or sacred in their life.

Surveys have demonstrated that patients want us to be fully present to them and not to just fix them. Compassion is a patient need. People want and need presence. In a US study of hospitalized patient the number one spiritual need is love and belonging.[24] The studies of Gerotranscendence also demonstrate the importance of witness and of contemplative practice in the clinical setting. Our clinical places for the elderly do not support the final spiritual stage of life. Quiet, not forced activities may be what is needed. Compassionate presence and witness may, at the time of deep suffering, be more important than rituals or activities that may be meaningless at that time for people. In our loving the elderly, they find love within themselves.

Teresa of Avila writes, "His Majesty, in saying that the soul is made in his own image, makes it almost impossible for us to understand the sublime dignity and beauty of the soul."[25] She also writes, "Just as it doesn't do us any harm to reflect on things in heaven…it doesn't't do us any harm to see that it is possible for so great a God to commune with such foul-smelling worms; and upon seeing this, come to love a goodness so perfect and a mercy so immeasurable."[26]

Teresa's words inspire us to reflect on our own practice with our patients. Are we objectifying patients because we cannot bare their suffering? Can we be compassionate to the poor, the ill? And can we hear the cries of the patients in nursing homes, hospitals, and in other health settings?

To be compassionate is challenging. As McNeill writes, "Compassion asks us to go where it hurts, to enter into places of pain, to share in brokenness, fear, confusion, and anguish. Compassion challenges us to cry out with those in misery, to mourn with those who are lonely, to weep with those in tears. Compassion means full immersion into the condition of being human."[27]

Compassion challenges us to see the face of the sacred in the person we are serving. But in order to be able to do that, we must see the sacred within ourselves. Our own sense of meaning and purpose, our awareness of our call to serve, our sense of connection to the significant or sacred, all enable us to embody ultimate love for the other. In seeing the sacred in the other, we can honor their dignity and respect the person without hiding behind the religio- or medical-technical aspects of our professions. It is only then that the patient currently lying alone in the hospital wards or nursing homes will no longer cry out in silence but instead with feel the compassion of the witnesses – the doctor as witness, the nurse as witness, the therapist as witness, the chaplain as witness, and the clergy as witness.

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2. The Theology of Prevention Between Love and Responsibility: Towards Health of the Mind and the Body

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Founder of the 'Shalom' Movement,
Italy,
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Nothing is more fascinating in our eyes than the immense work of the creation which expresses the ineffable intelligence and creativity of the Creator. The progressive investigations of science have revealed the extraordinary divine power that concealed everything in the heart of a star gravid with life that exploded millions and millions of years ago. What our bodies are made of, bone, flesh and blood, was already there, in that valuable casket that suddenly opened. Once the clock of time had been activated, complex conditions followed which allowed man to exist. Everything was chaos and order was brought in with wise, silent and patient action. The sublime Vase-maker took millions of years to shape his masterpiece – man, such as we are nowadays. The seven billion living humans today on earth, without taking into account all those who have preceded us, bear the impress of uniqueness. Not even monozygotic twins, who are said to be identical as regards the genetic patrimony that they have inherited from their parents, are ever completely identical as regards their external looks and their personalities.

We are led to exclaim with the psalmist: 'the glory of God is man fully alive' (Ps. 144). Wonder grips us when we reflect upon the mental and spiritual faculties of man, when we explore the infinite meanders of consciousness, where the invisible artist dialogues with his creature. In order to understand man identified as body and mind we have to exclude the possibility that everything was born by chance, with everything reduced to a molecular accident. The light of the truth of man is revealed by Holy Scripture: 'and yet you made him a little below the angels'(Ps. 8:6). The Hebrew word used to refer to man is '*basar*' which primarily means 'flesh' and, more broadly, 'body', as a human being understood in his or her totality and completeness. The evocative image of Ezekiel 27 imagines a creative restructuring of living man that starts from the bones on which are formed the nerves, then the flesh, the skin and lastly the spirit which gives them life. The ancient believing Jew knew that the human being is made up of a multiplicity of elements that are unified and are vitalised by the 'breath' of spirit which he imagined circulated in the blood. The corporeal structure in its visibility and its physicality characterises and denominates living man. The body is the person inasmuch as he or she is called by God to existence at conception onwards and remains such until his or her natural sunset. His limbs and his mental and physical energies place him in a vital and fecund relationship with other people and with things. Jesus himself, the Word made flesh, who took a body from Mary, is the teacher of life and teaches us to take care of our bodies and those of other people; he was concerned about the absence of food (Mk 6:37-43), and of health (Lk 7:21), and invited his friends to rest for a little while (Mt 6:30-31). The body is also the primary expressive instrument of human interiority through the face. We remember the very many phrases about the Face of Christ that are to be found in the Gospels.

To the teacher of the law, who wanted to put him to the test (Lk 10:25-29), Jesus restated what the Levite taught: love for one's neighbour commensurate with love for oneself. The care and concern that we should have towards the body that has been given to us by God must also be directed towards our fellows, to our neighbours. It is interesting to observe that it was the teacher of the law himself who, in the meeting with Jesus, reduced to only one the two principal commandments: 'you will love the Lord your God…and you will love your neighbour as yourself'. To love as yourself means that you love the other only if you love yourself, not in a selfish sense but simply to steward the gift of God that we are, to render glory to God, conserving our health as well, something that will allow us to serve other people with greater devotion and efficacy. Anthony the Great added that 'nobody is worse than he who is bad with himself: he who loves himself loves everyone'. To attend carefully to our physical, mental and spiritual health is thus a precise moral duty, it leads to an improved quality of life, and is like a contribution that is offered to a better society, to the common good. Health is the outcome of various factors, the so-termed 'health determinants', made up of the genetic inheritance, personal behaviour and lifestyle, social, cultural and economic factors, our work situation, access to health-care services, and the environmental context.

These factors have a different impact on the state of health of an individual and the state of health of a community (Institute for the Future (IFTF), *Health and Healthcare 2010. The Forecast, The Challenge*, Jossey-Bass, Princeton, 2003). Thus health depends 50% on behaviour and lifestyles, whereas the environment is responsible for a figure of 20%, like, indeed, the genetic component (20%). The remaining 10%, lastly, is to be attributed to health-care services.

These aspects explain why 80,000 years were needed for the human species to move from an average life span of twenty years to one of forty, whereas not even a century, the last of the second millennium, was needed for a further extraordinary doubling of this figure. Thus in the most advanced countries average life expectancy is by now near to eighty years. In other terms, during the course of the last 170 years, average life expectancy in industrialised countries has increased by 2.5 years every ten years: more or less, six hours a day.

We should prepare ourselves, however, for another leap forward. Some recent studies on the biology of ageing seem to confirm what is observed in the Book of Genesis (6:3): 'Then the Lord said: "My spirit shall not remain in man forever, since he is but flesh. His days shall comprise one hundred and twenty years'. The Bible, for that matter, tells us about at least thirty-three people who lived more than 123 years. (It escapes us whether these were symbolic or historical numbers).

Given the research available to us, the human organism is said to have genetic equipment, which was defined over the space of 150,000 to 300,000 years, which is held to confirm upon it the potential to live for well beyond a hundred years. However this maximum limit is influenced 70-80% by lifestyle and by numerous environmental factors. Thus what determines the length of the life of an individual is not so much an unchangeable element, for example his or her genetic inheritance, as modifiable factors such as behaviour and socio-environmental conditions.

There is, however, another aspect connected with lifespan: the quality of life of the years that have been gained. One indicator, life expectancy in years without disability, according to data of the year 2008, is 7.9 years for male and 7.2 years for females. This means that we have added many years to our lives but less life to our years. This observation involves a reality: the population of industrialised countries is ageing and the incidence of chronic degenerative illnesses, that is to say ones linked to modifiable factors, is on the increase, because of a lack of preventive action as well. The consumption of alcohol, smoking, a sedentary life and obesity are forms of behaviour that work together in increasing the incidence of chronic degenerative illnesses.

There are three challenges that the system of protection in industrialised society already has to face: the ageing of the population, chronic illness, and absence of self-sufficiency.

Chronic degenerative illnesses alone, some of which can be prevented by adopting healthy attitudes, make up 30% of health problems but absorb 70% of the resources allocated to health. In this sense prevention can do a great deal to avoid important consequences, such as expenditure that take away resources from other situations that cannot be equally addressed.

At least fifteen vaccines are effective in the control of infectious diseases. Screenings exist that are able to improve in a marked way death levels caused by breast cancer, uterine cervix cancer, prostrate cancer and colon cancer. Organisations, communities and also individuals have a responsibility as regards their own health and the resources that are employed to protect it.

Side by side with this commitment, which we may say is of a 'lay' character, there is another ethical-religious one which for Catholics in particular has a fundamental value, to the point that one can speak about a 'theology of prevention' that should investigate and promote the stewarding of the body, starting with warning of St. Paul: 'Do you not know that your body is a temple of the holy Spirit within you, whom you have from God, and that you are not your own? For you have been purchased at a price. Therefore, glorify God in your body' (1Cor 6:19-20).

The Apostle of the Nations calls on every Christian to decide how to use his or her body: according to the 'flesh', and therefore not respecting it, or by involving also the corporeal in its Christian dimension. The *Catechism of the Catholic Church* specifically addresses this aspect in articles 2288–2290. In particular, it is the first statement of article 2288 that summarises the relationship between prevention and morality. Indeed, it observes that: 'Life and physical health are precious gifts entrusted to us by God. We must take responsible care of others and the common good' At the same time, however, it warns against exaggerating this care to the point of transforming it into a *cult of the body* (2289) of a pagan character.

The *Catechism of the Catholic Church* also dwells upon the promotion of lifestyles when, with reference to the virtues of tolerance, it commits Christians to avoiding 'every *kind of excess*: the abuse of food, alcohol, tobacco or medicine' (2290).

Prefiguring from many points of view the advice of international health-care organisations, the *Catechism of the Catholic Church* observes that: '*Concern for the health* of its citizens requires that society help in the attainment of living conditions that allow them to grow and reach maturity: food and clothing, housing, health care, basic education, employment and social assistance' (2288).

According to experts in the field of bioethics, a failure to attend to one's own health is to be seen as a grave ethical wrong, and thus taking care of oneself is to be seen as a moral duty and a responsible act of charity towards ourselves and other people.

Medical science has always been active in the field of prevention and in the promotion of correct lifestyles, even though approaches not consonant with the principles of prevention itself cannot be defined as sinful. One is dealing more with appealing to common sense, or better to a sense of charity which is placed, in its turn, in front of ineluctable duties.

Prevention, therefore, calls on individual responsibility as regards lifestyles and forms of behaviour as summarised by the WHO (World Health Organisation): not smoking, consuming limited quantities of alcohol, following a suitable diet, not being exposed excessively to the sun, controlling one's weight, engaging in regular physical activity, and sleeping for a sufficient number of hours, something that has a beneficial effect on these other healthy initiatives. To these invitations should be added another: being subject to screenings.

At a doctrinal level, adherence to preventive practices belongs to the exercise of virtues in relation to oneself on a par with temperance, prudence and charity towards other people.

Although it is true that in economically advanced countries great advances have been achieved as regards taking care of the body, perhaps not equal attention has been paid to the spirit. Unfortunately, the news places before our eyes cases of murder and suicide, as well as physical and verbal violence which indicate profound mental suffering.

Mental disturbances and personalities disturbances are the symptom that tells us that in our society there is a present a malaise as regards living which is derived from a lack of values, by an incapacity to communicate and by loneliness. One hears these problems being spoken about but effective prevention is not implemented. The chasm of emptiness, which is being created around and inside the individual, often leads him or her to look for artificial paradises that lead him or her to his or her total destruction.

In this area, families, schools and parishes must act so that words like 'friendship', 'solidarity', 'understanding' and 'love' become customary.

Only in this way can contemporary man go back to respecting himself, his fellows and all creatures on the earth.

Prevention, to achieve health of the body and of the mind, thus requires a virtuous approach (*secundum rationem*) that avoids excessive fears and leads people to accept serenely both illness and the features of ageing and death (*L'agire morale del cristiano*, edited by Licio Melina, 2002, vol. 2, p. 162). ■

3. SPIRITUAL AND PASTORAL ACCOMPANYING

3.1 Spiritual and Pastoral Accompanying in Places of Treatment and Care

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The Church has the mission to care for the sick and suffering and to be at the service of sick elderly people. Yet what does this mean as regards people with neurodegenerative pathologies? Do they require “specific” spiritual or pastoral care, and if so, what do they expect and what do they require?

First one has to ask about the “giver” and the “receiver” of such spiritual and pastoral accompanying in places of treatment and care. Do health-care professionals (i.e. medical doctors and nurses etc.) really offer what is needed or are they just following their circumscribed and specific professional duties? Are they also able and willing to care for their patients’ spiritual needs (Büssing *et al.*, 2013, 2014; Offenbaecher *et al.*, 2013), or is this the job of certified pastors? What about elderly people who live in retirement or nursing homes (with or without neurodegenerative or cognitive impairments): do they really need what is offered? Do health-care professionals and pastors really know what elderly (Erichsen and Büssing, 2013) and chronically ill persons need (Büssing *et al.*, 2010, 2013, 2014)? Are we really able to respond specifically beyond a well-organized daily routine?

The Spiritual Needs of Patients with Chronic Diseases

Physicians have to recognize that their patients with chronic diseases may have unmet spiritual needs (Balboni *et al.*, 2007, 2010) – in secular societies as well (Büssing and Koenig, 2010; Büssing *et al.*, 2010, 2013, 2014; Offenbaecher *et al.*, 2013; Hoecker *et al.*, 2013). These needs are in most cases addressed neither by the medical system nor by a religious community (which might be seen as responsible for caring for these needs). Even in more secular Germany, the majority of tumor patients wanted their doctor to be interested in their spiritual orientation (Frick *et al.*, 2006). Studies among patients with chronic pain diseases found that 23% would have liked to talk with a pastor/chaplain about their spiritual needs, 20% had no one to talk abut these issues and for 37% it was important to talk with their medical doctor about their spiritual needs (Büssing *et al.*, 2009). Yet medical practitioners may lack the necessary time, skills or even interest to uncover and address these needs.

What are these spiritual needs that patients with chronic diseases may refer to when they are asked? Among German patients with chronic pain diseases and cancer (61% were nominally Christians, 3% had other religious affiliations, and 36% had none), *religious needs* (i.e. praying, taking part in a religious ceremony, reading spiritual/religious books, turning to God, etc.) and *existential needs* (i.e. reflecting on one’s previous life, talking with someone about meaning in life and suffering, dissolving open aspects in life, talking about the possibility of a life after death, etc.) were of some relevance only for patients with cancer, but not for patients with chronic pain diseases. Instead, needs for *inner peace* (i.e. the wish to dwell in places of quiet and peace, plunge into the beauty of nature, find inner peace, talk with other people about fears and worries, higher devotion by others) and *giving/generative* needs (i.e. the intention to provide solace to someone, to pass on one’s own life experiences to others, and to be assured that your life has been meaningful and of value) were of high relevance to them (Büssing *et al*. 2013). In all cases, patients with cancer had the strongest needs compared to patients with (primarily non-fatal) chronic pain diseases.

A similar pattern of spiritual needs was found in patients with chronic diseases (66% cancer, 34% other chronic conditions) in Shanghai who had predominantly no specific religious affiliation (77%) (Büssing *et al.*, 2013b). In contrast, Catholic patients with chronic diseases (35% cancer, 66% other chronic conditions) in Poland stated high *religious needs* and *existential needs*, and high needs for *inner peace* and *giving/generation*.

Thus, the pattern of unmet spiritual needs and their self-ascribed magnitude depends on various influencing factors, which include gender, religious orientation and culture. Moreover, not all needs are necessarily "spiritual". For example, the need for forgiveness may have a different meaning for a-religious patients compared to religious patients. Nevertheless, in both cases pastors and/or psychologists have to respond to such needs adequately, whatever the contextual interpretation may be. The need to be forgiven may mean to let go feelings of guilt, shame and failure, on the one hand, and also to seek reconciliation with either concrete persons (whether they are available, absent or deceased nor not) or with God, on the other. Both acts of reconciliation may result in a reconnection with others or with the Sacred (*religio*) which is regarded as liberating (salvation).

The Spiritual Needs of Elderly People Living in Retirement/ Nursing Homes

What specific spiritual needs were reported by elderly people living in retirement or retirement nursing homes? These elderly are not necessarily sick – they are only less "productive" than before.

In elderly people in North-Germany with a mean age 84 ± 7 years, all spiritual needs scored much lower compared to relatively younger patients with chronic diseases (Erichsen and Büssing, 2013). *Religious needs* and *existential needs* were of low relevance to these elderly persons, while *inner peace* needs were in some and needs for *giving/generation* were of the highest relevance.

Interestingly, the magnitude of unmet spiritual needs was completely different in elderly people in the northern and southern parts of Germany. While in the North most were Protestants (Erichsen and Büssing, 2013), the elderly from the South were mostly Catholics (Man Ging *et al.*, submitted for publication). In the Catholic South, *religious needs* scored high and the other needs were relatively low, whereas in the Protestant North of Germany, *inner peace needs* and *giving/generation* were of relevance but not *religious needs*. Interestingly, religious trust scored much higher in elderly people in the South compared to those in the North, while self care abilities had no significant influence on the magnitude of stated spiritual needs (Erichsen and Büssing, 2013; Man Ging *et al.*, submitted for publication).

Detail analyses referring to these samples revealed that praying for oneself and participating in a religious ceremony (i.e. services) were of relevance to all of them, but in particular in elderly people in the South of Germany, while praying with someone else or the need for someone to pray for them were of some relevance for elderly people in the South, but of no relevance for elderly in the North. All these differences were significant from a statistical point of view (p<.0001; t-test).

The need to be forgiven was low in all elderly enrolled in both studies, and there were no significant differences between both samples. Yet, it is so far unclear whether these needs were low because the needs for forgiveness were already supported, or whether they felt that there was not much left to be forgiven.

With respect to relational needs – which are not necessarily spiritual – elderly people in the North had a strong need to feel connected with their families and to be invited to private meetings by friends, while these needs were significantly lower in people in the South (p<.0001). It seems that family support/access was much higher in the South of Germany, and thus these needs were not of high relevance to them. Interestingly, these relational needs did not refer to a pastor/chaplain from the respective religious community. In all cases, there was a low need for someone of the religious community to care, especially in elderly people in the North of Germany.

When elderly people were asked about their spiritual needs, several started to weep because they were never confronted directly with their inmost perceptions and they were never invited to talk about these perceptions and needs (Erichsen and Büssing, 2013). It is important to stress that the interviewees regarded these talks as liberating, pleasant and enriching. Although the interviewees' comments indicate that most felt connected with their families, on the one hand, or had the intention to connect with those who would remember them, on the other, they nevertheless feared burdening them with their own troubles, fears and worries, or feared that there was a limited interest in their concerns. A complication was the fact that closer relationships or confiding talks with other residents were rare; often they felt an impersonal, cool and egoistic atmosphere among the residents (Erichsen and Büssing, 2013). Thus, elderly people in retirement or retirement nursing homes were attended to but may nevertheless have felt lonely, and clearly required further support by caregivers, relatives and pastors.

Faith as a Resource in Individuals with Neurodegenerative Diseases

Multiple sclerosis (MS) is an "incurable" disease characterized by an often unpredictable course of exacerbations and remissions with a significant impairment of both quality of life and life goals (Bragazzi, 2013). Patients living with MS often experience social isolation, are depressed, and thus have a higher risk of suicide (Feinstein, 2002; Turner *et al.*, 2006; Pompili *et al.*, 2012).

A qualitative study among 7 patients with MS reported that their functional difficulties and psychological challenges were "ameliorated to some extent by an increased appreciation of life and spirituality" (Irvine *et al.*, 2009). Another qualitative study of 13 patients with MS found that adaptation to the disease was influenced by a variety of factors, including religion/spirituality (DiLorenzo *et al.*, 2008).

In empirical studies on patients

with MS, the positive effects of spirituality/religiosity were less clear-cut. While there were no significant associations between spirituality/religiosity and psychological adjustment or quality of life, patients' intrinsic religious orientations and quest religious orientations were associated with low psychological adjustment (Makros and McCabe, 2003). The authors suggested that either patients utilized their religiosity (i.e. praying) to cope with their health affections or they were more depressed because their religious activities did not result in the desired positive resolutions.

Because several patients with other chronic diseases (who are on average older than patients with MS) relied on their faith/spirituality as a resource to cope, one may ask whether relatively young people with MS may rely on this source, too.

In secular Germany, we performed a study to analyze the role of a person's faith as a resource to cope with MS. Among the enrolled persons (74% of a Christian denomination, 8% of other confessions, and 18% without any confession), 54% regarded themselves as neither religious nor spiritual (R-S-), 16% as not religious but spiritual (R-S+), 19% as religious but not spiritual (R+S-), and 20% as both religious and spiritual (R+S+) (Büssing *et al.*, 2013c). In this sample, 29% stated that their faith was a strong hoandle in difficult times, while 52% rejected this statement (19% were undecided). Only 6% mentioned that they had lost their faith because of distinct experiences in life. However, faith as a resource was neither related to a patient's disability, life satisfaction or fatigue nor to negative mood states; instead it was associated with an ability to experience gratitude/awe and with a reappraisal strategy in terms of a positive interpretation of their illness (i.e. reflecting on what is essential in life; illness has meaning; illness as a chance for development; appreciation of life because of an experience of illness) (Büssing *et al.*, 2013c). This ability to reflect and to deal differently with illness and life concerns was lowest in MS persons. They may either have no specific interest or are less willing to reflect these issues (Büssing *et al.*, 2013c). The crucial question is how to reach persons with MS to "open the door" towards their inherent spirituality and to reflect on what is essential in their lives.

What about the relevance of spirituality/religiosity in persons with other neurodegenerative diseases? In a longitudinal study that enrolled 70 patients with probable Alzheimer's disease, Kaufman *et al.* (2007) found that a slower rate of cognitive decline was associated with higher levels of spirituality and private religious practices (even when controlled for baseline levels of cognition, age, gender, and education), while there was no significant association between such a cognitive decline and patients' quality of life. A study by Coin *et al.* (2010) on 64 patients with Alzheimer's disease found that patients with higher religiosity had slower cognitive and behavioral decline within a 12 months' observation period than patients with low religiosity.

Both studies indicate that active engagement/involvement in spiritual/religious issues might be a crucial resource for patients with Alzheimer dementia. Indeed, when higher levels of religiosity are associated with slower progression, one nevertheless has to be aware that religious practices cannot be "prescribed" to slow down neurodegenerative processes. Moreover, there might be several other variables which could contribute to the positive effects observed in these persons.

While it is of importance that spirituality may indeed be associated with better health behavior (Hoff *et al.*, 2008), and better health outcomes under specific conditions (Chida *et al.*, 2009), it is important to underline that spirituality is not a "tool" to promote health. A person's spirituality (or more specifically, his faith) is first of all a matter of connectedness with the Sacred – whatever the health conditions might be.

The Spirituality of Caregivers

Pagnini and co-workers (2012) investigated 37 people with sporadic amyotrophic lateral sclerosis (ALS) and their caregivers, and found that the existential well-being and spiritual attitudes (i.e. "My religion has been a source of strength or comfort to me"; "I consider myself to have been religious or spiritual") of patients with ALS were positively correlated with their caregivers' existential well-being and quality of life. Conversely, patients' existential well-being and spiritual attitudes were negatively correlated with their caregivers' anxiety, depressive symptoms and care burden. These findings indicate that patients' well-being can be the "mirror" of their caregivers' well-being, and thus, both the patients and their caregivers need psychological and spiritual support.

Support for this observation comes from a randomized study of Grepmair *et al.* (2006, 2007) of psychotherapists in education. They reported that patients of those psychotherapists who were attending meditation courses promoting mindfulness had a significantly better symptom reduction (i.e. Global Severity Index and 8 SCL-90-R scales, including somatization, insecurity in social contact, obsessive behavior, anxiety, anger/hostility, phobic anxiety, paranoid thinking and psychoticism) than patients of those psychotherapists in education who were not meditating. These more mindful psychotherapists were probably more aware of their own spirituality, their own reactions, and more aware of their patients' feelings and behavior – and thus able to respond adequately. This means, to respond in a compassionate and deeply caring way, health-care professionals also require awareness of, and access to, their own spiritual resources, and regular reminding of their primary motivation to help others.

However, several physicians are reluctant to address patients' spirituality/religiosity during their daily routine. Among 770 medical doctors in North Germany (49% Protestants, 13% Catholics, 6% other, 32% no religious affiliation), the majority (67%) addressed spiritual issues seldom or never with their patients (Voltmer *et al.*, 2013). Those physicians who are regularly engaged in religious services or activities addressed such spiritual/religious issues among their patients more often than those who were less frequently engaged (Voltmer *et al.*, 2013). This behavior seems to be a matter of "professional neutrality" which is indeed appropriate in several cases, particularly when patients feel offended by institutional religiosity, but it might be less useful when patients rely on their faith as a resource to cope, or when they have circumscribed spiritual needs.

Indeed, among a sample of US physicians (39% Protestants, 22% Catholics, 29% other, 11% no religious affiliation) (Curlin *et al.*, 2006) and German psychiatrists (71% with a religious affiliation, 29% without) (Lee and Baumann 2013), most regarded it as appropriate to inquire about patients' spirituality/religiosity and to discuss such issues only when a patient brings them up. Most German psychiatrists regard it as inappropriate to talk with their patients about own religious beliefs or experiences (80%), or to pray with them (90%) (Lee and Baumann 2013), while for only some US physicians it was never appropriate to talk with patients about own religious beliefs or experiences (14%), or to pray with them (17%) (Curlin *et al.*, 2006).

The most frequently mentioned barriers to integrating spiritual/religious issues into therapeutic work in both samples of medical doctors were professional neutrality and lack of time (Curlin *et al.*, 2006; Lee and Baumann 2013). Professional neutrality was mentioned much more often in German psychiatrists than in US physicians, while US physicians mentioned lack of time, lack of knowledge and general discomfort more often than German psychiatrists. Interestingly, German psychiatrists argued that SpR issues were not their responsibility (Lee and Baumann 2013).

All this seems to be also a matter of relating and communicating. Scottish patients with advanced states of fatal diseases and their carers were indeed generally reluctant to raise spiritual issues but many were able to talk about their needs when they were able to develop a relationship (Murray *et al.*, 2004). Patients were best able to engage their personal resources to meet their spiritual needs when they were esteemed and valued by health professionals (Grant *et al.*, 2004).

When a degrading mental process "steals personhood and destroys our opportunities to heal, reconcile and deepen our relationship" with these persons (Angelica, 2013), this is in fact a significant (and depressive) challenge to caring for these patients. Rituals might be an option to connect persons with dementia emotionally to their true selves, with the participation of other people (i.e. family relatives and caregivers), and with the Sacred which might be experienced through these rituals.

Conclusions

It is important to note that patients may have specific unmet spiritual needs – even a-religious/skeptic patients (Büssing *et al.*, 2013a). These have to be recognized and addressed by certified pastors but also by health-care professionals – who might be the first in charge to identify such needs – and maybe also patients' relatives. Medical professionals have to go beyond their "not-my-job" attitude and reconsider their primary intention to help others as "Good Samaritans". A modern health-care system has to recognize and support a patient's spirituality/religiosity not only at a theoretical level but also at a very concrete one. Both are required: pastoral care by certified pastors and committed spiritual accompanying by medical doctors and nurses.

When we really believe that we encounter Christ in each and every person left on their own, we have to consider structural and individual changes. 1) *Structurally*: adequate time to nourish health-care professionals' own spirituality; time to develop a multi-professional "team spirit" (including patients' relatives); the encouragement of health-care professionals by the hospital organization to respond to patients' unmet spiritual needs as a prerequisite for appropriate and comprehensive health care; and spiritual/pastoral care for health-care professionals as well. 2) *Individually*: compassionate encounter with the patient; careful listening to what is said and not said; assuring the individual patient that he or she makes the difference; and the encouragement of patients to open towards their (inherent) spirituality when appropriate.

These basic steps towards adequate and patient-centered spiritual and pastoral accompanying in places of treatment and care can be substantiated by the recommendation of the Consensus Conferences to improve the "quality of spiritual care as a dimension of palliative care" (Puchalski *et al.*, 2009, 2014).

Lastly, an ancient letter from the first century calls our attention to an essential truth which we may also link to our work with the sick, lonely and suffering: "We are afflicted in every way, but not crushed; perplexed, but not driven to despair; persecuted, but not forsaken; struck down, but not destroyed; always carrying in the body the death of Jesus, so that the life of Jesus may also be manifested in our bodies." (2 Corinthians 4: 8-10). ■

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Notes

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3.2 Spiritual and Pastoral Accompanying in Local Contexts

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‘Nobody Should Suffer’

The subject that I would like to share with you is the activity engaged in for over twenty-five years directed towards accompanying and comforting sick people in the diocese of Lomas de Zamora, in Buenos Aires, Argentina.

Everyone knows, as Paul Claudel says, that ‘God did not come to eliminate suffering or even to explain it. He came to fill it with His presence’. Jesus calls us to this, to go – as the Pope asks us – to those existential outskirts of pain, public hospitals, which should have a privileged place in the hearts of our communities.

The Lord, during his public life, created an intense dynamism of communion with the suffering through contact with the sick. He touched them, and this included lepers who were the most excluded of all.

Those who want to understand the relationship between charity and devotion to caring for the sick in a right way must understand that moment, that turning point in the history of humanity that Jesus was and Christ in his ministry dedicated a great deal of attention and a great deal of time of the sick.[1]

In the hospitals of my country, where care and treatment are free, the poorest are cared for, some of whom are truly marginalised and are called ‘social’, and these are in particular middle-aged men and elderly people. For us they are a challenge as regards helping them and accompanying them during their illnesses and loneliness. This is the need of our hour which must be a ‘new hour’,[2] which asks creativity of us because ‘this is the hour’, as John Paul II said, ‘for a new hour of creativity of charity’,[3] so that every poor person feels that he or she is a part of the family of God since ‘the Church wants to be the Church of everyone, and especially the Church of the poor’.[4]

Today more than ever before pastoral care in health and for life must be a priority, especially as regards the concerns of pastors.[5]

For some time we have had a motto that expressed the aim of our task: ‘that nobody should suffer’. This is an exigent and demanding motto: for this reason everyone who feels that they are called by the Spirit of God to be engaged in such a task are required to have dedication and commitment in relation to their brothers and sisters who in illness, in suffering and in pain, make Jesus Christ, the Older Brothers, the ‘Man of Pains’, be amongst us.

The Lord asks us to go on a pilgrimage towards the sick, in the way Jesus did, that is to say understanding, listening and above all comforting so that they feel the caress of God and rediscover a hope that has often been lost.

Voluntary Work: Witness to the Fact that God is ‘Rich in Mercy’ (Eph 2:4)

‘Blessed be God the Father, and the only begotten Son of God, and the Holy Spirit, because His love for us is great’.[6]

In antiquity the people of Israel had a profound experience of divine mercy. The People of God implored God’s mercy not only when faced with moral evil or sin but also when they were afflicted by physical evil. This is what David did through awareness of the gravity of his guilt and what Job did during his great tribulations.[7]

In the ‘fullness of time’, God the Father wanted to reveal His mercy as He had never done before and as He would never do again. Since then, divine mercy shines forth on a tangible face – that of Christ.

Jesus of Nazareth ‘not only spoke about it and explained it through the use of parallels and parables, but, and above all else, he himself embodied it and personified it. *He himself is, in a certain sense, mercy*. For those who see it in him – and finds it in him – God becomes particularly ‘visible’ as the Father ‘rich in mercy’.[8] Christ fully showed that the Father is merciful, above all else on the cross and in his glorious resurrection. He himself effused his mercy on the world on the day of Pentecost when he sent the Holy Spirit who in the Trinity is the Love-Person. Thus, therefore, the paschal mystery, the mystery of the cross, is the mystery of mercy: the cross if the deepest inclination of the Divinity towards man and towards everything that man – in particular during moments of difficulty and pain – calls his unhappy destiny. Following in the footsteps of the Tradition of the Old Testament, of Christ himself and of the Apostles, the Church must bear witness to a God who is rich in mercy in all of her mission. Through words and through works, especially those of mercy. ‘I was sick and you visited me’ (Mt 25:36) [9].

Voluntary Work: a Response to the Mandate of Christ…

‘Christ has taught us that “man not only receives and experiences the mercy of God, but is also called “to practise mercy’ towards others: “Blessed are the merciful, for they shall obtain mercy’ (*Mt* 5: 7)”. He also showed us the many paths of mercy, which not only forgives sins but reaches out *to all human needs*. Jesus bent over every kind of human poverty, material and spiritual'.[10]

There is another reason why the disciple of Christ is called *to use mercy*: Jesus himself, Lord and Teacher, wanted to identify himself with the poor and the suffering: 'Each time that you did it to one of the least of my brethren, you did it to me'.[11] 'For by His incarnation the Son of God has united Himself in some fashion with every man'.[12]

…and Participation in the Merciful Mission of the Church

The mission of the Church is a mission of divine mercy and, in addition to imploring it emphatically through prayer, the Church is called *to embody it*, extending in this way the ministry of her Lord who passed by doing good: 'During his mortal life he passed by helping and healing all those who were prisoners of evil. Still today as a Good Samaritan he comes to the side of each man bent in body and spirit an pours upon his wounds the oil of consolation and the wine of hope'. [13]

In this embodiment, figures such as the Good Samaritan of the parable of Luke[14] and the episode of the visit of Mary to Elizabeth[15] are certainly a source of inspiration. One could say that there is a certain resemblance between the two icons. Like the just man of the parable, Mary, too, 'made herself a neighbour' to Elisabeth, she was able to go towards a human being who although she did not suffer from a physical malady was in need. Mary, the Mother of Life, *stopped, had compassion and provided help* (the three movements of the Samaritan) to her elderly cousin who, like her, was about to become a mother. In her visit, Mary exercised the mercy of which she was the bearer in the Magnificat: 'from generation to generation her mercy for those who fear him'.[16] And for this reason in this context she also appears as a Mother and Model of mercy. 'The Virgin in her own life lived an example of that *maternal love*, by which it behoves that all should be animated who cooperate in the apostolic mission of the Church for the regeneration of men'.[17]

Nowadays, one way by which to 'embody' the mercy that we are talking about is the exercise of hospital voluntary work, which, fortunately, is undergoing a gradual growth in our diocese and in many other places. In faithfully carrying out his or her service, a voluntary worker takes part in the merciful mission of the Church and by his or her personal and institutional activity makes the maternal love of the Church present.

Voluntary Work Must Take Place in an Ecclesial Way

In order base oneself on motivations that have their roots in the Word of God and given that this is an initiative that springs from the Christian community, it is starting from all of this that a voluntary worker is 'sent out'. He or she is called to act in an *ecclesial way*, avoiding all forms of individualism. 'Apostolic individualism, more than a lack of meekness or a tactical error, is a *doctrinal error*'.[18]

Indeed, how is it possible to operate in an isolated way of the Church has been 'unified by virtue of and in the image of the Trinity'?[19] Is this not a practical heresy'? We should, therefore, act collectively, in communion, because the Church, the icon of the Most Holy Trinity, is also communion.

To act in an ecclesial way means for the voluntary worker 'a dual belief'.[20] The service that is carried out *on behalf of the Church* 'is never an individual and isolated act'.[21] This service must be engaged in with a *unity of criteria*, following the rules indicated by the Church herself, remembering that no voluntary worker is the 'absolute owner' of his or her charitable service. In this way a Christian voluntary worker is Good News for the world of health and health care, a clear sign of life that proclaims with simplicity in the face of all forms of dehumanisation and death that *life will win*. On this subject Pope John Paul II wrote: 'It would therefore be to give a one-sided picture, which could lead to sterile discouragement, if the condemnation of the threats to life were not accompanied by the presentation of the positive signs at work in humanity's present situation… Increasingly, there are appearing in many places groups of volunteers prepared to offer hospitality to persons without a family, who find themselves in conditions of particular distress or who need a supportive environment to help them to overcome destructive habits and discover anew the meaning of life'.[22]

In our diocese the instrument for this implementation of this apostolate is the *'Mary Mother of Life Diocesan Voluntary Association'* which has its origins in the parishes and offers service in the state hospitals with a profoundly diocesan spirit. The fundamental point as regards helping the sick is to allow them to live their illnesses as an experience of grace through a 'helping relationship'.

The principal target of the 'Mary Mother of Life Voluntary Association', which is recognised as a Private Association of Faithful, is those sick people who are most abandoned. Without any spirit of proselytism, the volunteers speak about God through their looks, their listening and their actions – giving people food to eat, cleaning, listening and in particular comforting.

The volunteer is introduced to the parish priest and after three months of training goes to the hospital accompanied by another volunteer. Lastly, in her parish she promises to serve the most abandoned sick people for a year, a promise that is renewed every year on the day of St. Camillus.

This kind of voluntary work now celebrated twenty-five years of service in the year 2012 and has been recognised at a diocesan level since 2002.

In recent years some services have arisen within this voluntary work: that of 'Mother Mary' which is made up of mothers who serve the poorest and most vulnerable women who are about to give birth; and the 'Volunteers of the Holy Cross' which is made up of men who care for their sick and alone peers. This is a service that is engaged in during the night.

This meets the invitation of Pope Francis to 'go towards the flesh of Jesus that suffers'[23] in the person of sick people.

As the Diocesan Delegate for Pastoral Care in Health and for Life, I thank the Pontifical Council for it kind invitation and I thank you all for having listened to me. Thank you very much.

Notes

[1] Cf. Lk 4:40; Mt. 9:35.

[2] Msgr. G. B. Montini, 'Message when Entering the Archdiocese of Milan', 1955.

[3] John Paul II, *Novo Milenio Ineunte*, n. 50.

[4] John XXIII, Radio message, '*Ecclesia Christi*', n. 3.

[5] *Pastores Gregis*, 71.

[6] Mass of the solemnity of the Most Holy Trinity. Entrance Antiphone.

[7] Cf. *Dives in Misericordia*, III, n. 4.

[8] *Ibid*., n. 2.

[9] Cf. *ibid*., n. 8.

[10] John Paul II, Homily for the Canonization of the Blessed Faustina Kowalska, Apostle of the Merciful Jesus', 30 April 2000.

[11] Mt 25:40.

[12] *Gaudium et spes*, n. 22.

[13] Common Preface VIII.

[14] Lk 10: 29-37.

[15] Lk 1:39-45.

[16] Lk 1:50.

[17] *Lumen Gentium*, n. 65.

[18] Pius XII, 'Address to the Congress of Workers at Versailles', 1957.

[19] *Prefazio domenicale VIII, Tempo ordinario.*

[20] Cf. *Evangelii Nuntiandi*, n. 60.

[21] *Ibidem*.

[22] *Evangelium Vitae*, n. 26.

[23] Pope Francis, 'Address to the Ecclesial Conference of the Diocese of Rome', 17 June 2013.

3.3 Spiritual and Pastoral Care Inside the Family

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The Impact of the Social Network in Times of Crisis

Religion is humanity's oldest system of trauma care. This is an understanding I have gained from my many years of active participation in the field of psychotraumatology. Well, being old or dying in themselves should not be traumatic situations, but as the last period and the natural endpoint of our earthly life, they evoke fear and other intense emotions. It often happens that people are scared of this time; the dying as well as the people that form their social context: Because, the reality of what may or may not be beyond is not accessible to our direct experience. In fact, death and the "hereafter" forever have always been subjects of faith and hope.

At the threshold of death, the *concept of self and the world* formed by the individual must be proven as stable. This is similar in other existentially burdening or traumatic crises. Today we know that a successful passing through such times of crisis always vitally depends on this *concept of self and the world* which we see as the spiritual dimension of human life. Convictions, experiences and desire carry this dimension of life and survival and form the foundation of our identity and our basic feeling of security.

But for the individual who finds him/herself in a highly straining and fearful situation, this personal foundation of life often appears not to be sufficient and strong enough; or when dementia or other diseases combined with altered states of consciousness constrict the access to the individual's *concept of self and the world.*

This is precisely when community, the social dimension and social connections come to our aid. Martin Buber expressed this in his well-known phrase: "The human being is formed "I" by the "You". The religions, meant as cultures of spirituality and common religiosity, have always granted this truth structure and stability, mediated by the family, the neighborhood and the clan.

When an individual's *concept of self and the world* reaches its limit, religion connects the individual – his or her convictions and experiences – with those of the community.

Moreover, religion also connects the individual with the convictions and experiences of his or her forefathers and foremothers: Moses was told to motivate his people to exchange the security of Egypt with the ambiguity of the desert: "The God of your fathers has sent me to you… the God of Abraham, of Isaac, and of Jacob" (Ex 3).

Especially at the time of dying, a time of transition into an absolutely unknown future, the credibility offered by social relationships and religion has always had a central importance: To be part of a community means being a part of a shared meaning, a shared *concept of self and the world*, and possessing a treasure of common rituals. This community through its actions, symbols and words helps to actualize together and renew meaning and trust in life's foundations when it is most necessary.

The Concept of the Family in a Changing World

Since the subject of this presentation is "the family", I think it is necessary to understand this word as multidimensional. We need to go beyond the biological nuclear family of father, mother, and child and expand the concept to more than the sociological network of blood relationships and the various generations.

The cultural sciences today teach us that the concept of family is understood differently in every culture of the world, including concepts such as family of origin, nuclear family, extended family, extended blood or tribal family, actual community of life, people of one's own race or ethnicity, and also more and more one's own "circle of best friends".

Theology, too, gives us a different concept of a "family by faith" founded by baptism and therefore somehow separate and distinct from the family of birth.

In any case, no matter what concept of family one subscribes to, the family in all cultures is regarded as a very important system of survival in times of crises. The family steps in and offers the much needed credibility and stability of the foundational *concepts of self and the world*.

In a world that gives more importance to the individual than ever before and in a world of profound cultural changes, the term 'the family' and the importance of the family will be uniquely different for each individual.

Especially in industrial countries, the concept of the so-called "patchwork family" or the concept of the "family of friends" is growing.

An inherent challenge with these new family concepts is that often in times of crisis there is no common *concept of self and the world*. Frequently, those families lack commonly held and practiced rituals to actualize it.

While these kinds of family offer social support, compassion and practical help, often it has lost the function of implicit and explicit coherence of meaning and hope.

Spiritual Care for the Sick and the Dying by the Family

However the family is defined, it should offer a compassionate, meaning-instilling community not only for the dying individual. Spoken from the perspective of faith, in the context of the family God's promise of unconditional love and eternal life it is concretized and comes alive. When faced with impending death and an unknown future, the dying individual needs to experience through his or her loved ones that their hope and faith are real, trustworthy, and stable. This happens by being present together, by carrying the burden of the struggle together, and by searching for meaning and value together.

This also happens by remembering the various expressions of faith that have been significant for the individual since childhood, such as symbols, songs, lyrics and prayers. Especially for the elderly and those who deal with dementia, this search for something that they remember, and thus "own", can be a profound support on their journey to complete life.

Moreover, for the caring family the common remembrance of expressions of faith can become an experience of re-connection and a new way of communication with their loved ones, a feeling that for many is lost during the advance of the disease.

When faced with impending death and an unknown future, spiritual care for the individual by the family takes on special importance in the actions of *letting go* and *releasing/sending forth*. And for the dying this time holds the special meaning of handing over life (*bios*) and responsibility. Remember the story of Jacob and his father's blessing (Gen 27). This is not only about the transfer of material property: it is also about the empowerment to live one's own adult life into the future, which is as important for sons and daughters as it is for mothers and fathers.

When faced with impending death and an unknown future, the individual who fifty years ago promised their partner a life together in commitment and love, at the end of life needs to perform the actions of *letting go* and *releasing/sending forth*.

When faced with impending death and an unknown future, the individual who was bound to someone in love, needs a possibility to express this love and gratitude; a good word or a sign to give as a blessing to the one who begins their journey or as a gift to those staying behind.

At the same time, the moments of impending death and dying offer a time for reconciliation and a celebration of life's achievements. It is the last and urgent time to gather, reunite, celebrate, and forgive.

In my German culture today, many families have lost the practice of living together through this last time of life up to death and dying, and therefore many families these days experience a sense of being lost and uncertain. This is why good pastoral care for these families is important and helpful. Like a "Master of Ceremonies", the pastoral care provider can guide the dying and the family through the challenges of this time.

The Importance of Pastoral Care for Families

The end of life rituals of the Church for a long time have been narrowly seen as a process only between the priest and the dying person. Today we need a ritual that helps to embrace also the family members and facilitates their process of *letting go* and *releasing/sending forth*. We need rituals that embrace the family and assist family members not only with spoken prayers but also with symbolic, ritual acts, done together, which are more profound and effective in this final situation than words.

We need to provide signs and symbols to help people to *let go* and *release/send forth* the other with all their heart, even when the intellect may not quite be ready to do so.

At least in Europe the religions are no longer a common home for all people. Pastoral care should be able to connect people with different cultural backgrounds and beliefs as well as people without any religious experience who all find themselves standing around the bed of a dying family member. This is the challenge for pastoral care today: to offer our spiritual and religious experience to a very diverse and often unchurched population without losing our own identity of faith.

To help families in their challenge of spiritual care not only at the end of life, the Church must give them pastoral care workers who are able to do more than to read the book of rites.

Evangelization means to open a space for the deep spiritual experience that life is in the hands of God. End of life situations offer themselves as very challenging but profoundly grace-filled moments for this type of lived evangelization.

A pastoral worker today needs a caring understanding of a concrete situation, the ability to use traditional words and signs in a way that involves those who are present, the dying as well as the family. To achieve this we have to rediscover our old traditions and to fill them with new life.

We also have to develop and provide new rituals and signs that can adequately and meaningfully be used in challenging situations such as Intensive Care Units, Dementia and Alzheimer's Care Units or Vegetative State and Coma Care Units, and in other changing circumstances of life.

In this way religion can prove itself anew humanity's oldest system of trauma care and our Church can help families to live this challenging time together as a rich time of experience of community, meaning, promise, grace and hope as well. ■

3.4 Associations and Volunteers at the Service of Elderly People with Neurodegenerative Illness and their Families

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London, United Kingdom

My presentation will focus on one of the main neurodegenerative diseases, dementia, which including Alzheimer's disease is the most common type of dementia. These diseases are strongly related to ageing. The number of people with dementia was estimated at 36 million in the year 2010 and if we don't find a cure the ageing of the world population will increase this figure to 66 million by the year 2030 and 115 million by 2050. The majority of the cases of dementia occur in lower and middle-income countries and the global cost of dementia was calculated at US$604 billion for 2010, 1% of global gross domestic product (GDP). In other words, if dementia were a country, it would be the 18th largest economy, sitting between Turkey and Indonesia.

The impact of the disease may be huge for society but it is even more for the person with dementia, often described as a loss of self-control. The impact on both the person diagnosed and their caregivers is emotional, social and economic. People with dementia need a lot of care and this often implies that the primary caregiver (mostly the spouse or one of the children, often daughter or daughter-in-law) need to leave their job or work part-time in order to provide a good level of assistance. Research shows a high level of stress and even depression can incur as a result of caregiving as well as an impact at the rest of the family. On the other hand, many people feel rewarded by caring for a loved one and it can even make families stronger and bring them together. Research shows that the majority of people with dementia around the world are cared for at home and by their family.

Voluntary associations play an important role in supporting these families. A patient organisation often has three key roles: providing information; organising mutual support and advocating on behalf of patients and their families for more recognition of the disease and better health services. This is very similar within the Alzheimer movement, although organizations around the world are of course in different stages of development. Volunteers are often involved in all these key roles and in some association there are only volunteers with no paid staff. When the association can afford to hire paid staff, they will focus on developing the tools and materials, providing training for volunteers and family caregivers and working with health care professionals. Staff can also have more specialist roles in communication, fundraising, advocacy and public policy and even stimulating research.

Here are some examples of the kind of work undertaken by Alzheimer associations. Much of their focus is on ensuring that the public can recognise the first signs of dementia. Indeed, this is even the most visited page on the organisation's website. The Alzheimer's Association in the USA has developed a good tool to educate people, a simple list called the 10 Warning Signs. These signs include memory loss that disrupts daily life to more dramatic changes in mood and personality. If you worried you or a member of your family or friends might have dementia you can go through the list. If you tick multiple boxes a visit to your doctor or physician is advised. These signs are now translated in multiple languages and adapted to the local culture in many countries around the world.

The 10 Warning Signs:
1. Memory loss that disrupts daily life
2. Challenges in planning or solving problems
3. Difficulty completing familiar tasks at home, at work or at leisure
4. Confusion with time or place
5. Trouble understanding visual images and spatial relationship
6. New problems with words in speaking or writing
7. Misplacing things and losing the ability to retrace steps
8. Decreased or poor judgment
9. Withdrawal from work or social activities
10. Changes in mood and personality

It is clear sharing experiences between people with dementia and their caregivers is key in providing meaningful support to help them to live well with the disease.. Over the years a number of good models have been developed, such as Alzheimer's or Memory Cafes, where people easily can access information and speak to others and attend tailored support groups. Most Alzheimer associations have a help line that is often accessible 24 hours a day and 7 days a week for information and support. More recently the role of social media has become important as well and there are now many Facebook and Twitter pages where people with dementia or their caregivers can share stories and connect to each other.

Advocacy and public policy is another important area of work by voluntary organisations like Alzheimer associations. To advocate means to speak on behalf of someone who cannot easily do this, and in the early stages of the Alzheimer movement this was mainly done by professionals and family caregivers. But in the last ten years, more and more people with dementia, many of them in early stage of the disease, have become strong advocates and have spoken out in public about their experiences of the disease. This is important but needs to be backed up with providing the facts: what is the number of people living with the disease in my country, province or city? What is the societal cost of the disease and what services are available or should be provided? Patient organisations need to work on these questions before they can project their voice successfully. They also need champions within the government: politicians or civil servants who want to make the disease a priority. For dementia this has only started quite recently and still needs further development around the world.

Alzheimer's Disease International (ADI) is the global umbrella organisation of all national Alzheimer associations. It was created in 1984 and currently has member organisations in 84 countries. It aims to help establish and strengthen Alzheimer associations throughout the world, and to raise global awareness about Alzheimer's disease and all other causes of dementia, putting dementia on the global agenda as a health priority. ADI has a number of programmes to make this happen, including the Alzheimer University, a training programme for staff and volunteers of member associations and the ADI Twinning Programme where we link an established and emerging association together to each other learn from each other and create a mutually beneficial relationship.

The main activities of ADI for raising global awareness are an annual international conference that travels around the world as well as World Alzheimer's Month, which is the month of September, with World Alzheimer's Day on the 21st of September, the first day of autumn. The theme of World Alzheimer's Month 2013 was *A Journey of Caring*, emphasising the importance of the continuum of care for people living with dementia. 70 countries participated with a large number of national and local activities, around2,000 events around the world.

Alzheimer's Disease International is involving people living with dementia in all the things we do, like the conferences and Alzheimer Universities as well as advocacy work. There is a specific position for a person with dementia in the governing Board of the organisation and personal stories are featured in the *Global Perspective* newsletter every quarter.

Since 2009, ADI has released five World Alzheimer Reports, put together by leading researchers in the field through systematic reviews on the global numbers (2009) and global cost of the disease (2010), the benefits of early diagnosis and intervention (2011), overcoming stigma (2012) and long-term care in 2013. For the stigma report we did a global survey among people with dementia and their caregivers and learned that there is still a lot of social exclusion and lack of understanding of the disease within society. This can be tackled by a more inclusive approach that values people with dementia for what they still can do instead of the abilities they lost. Education of the public and awareness are key according to the majority of those that took part in the survey.

The 2013 World Alzheimer Report was released in September and contained an analysis of long-term care for dementia. A key finding was that currently 100 million older people worldwide need long-term car and that this number will almost treble by 2050 up to 277 million. Half of these will have dementia, so dementia remains the most important cause for the need for care. The report recommends a better integration of health and social care including training support for caregivers fundamentally, we need to make dementia a national health priority in every country.

ADI worked together with the World Health Organization on a report called *Dementia: A Public Health Priority* that was released in April 2012. It gives an overview of the research and knowledge on the main issues around Alzheimer's disease and other dementias around the world. A new finding in this report was that there are 7.7 million new cases of dementia every year, or one in every four seconds worldwide. The report calls for WHO member states to act now and develop national plans or strategies to deal with this epidemic. The report was originally released in English but has been translated in Chinese and Spanish and more translations are underway, including French, Russian and Arabic. It has been used by a number of governments to develop their own plans. Some countries already created such plans, such as Australia, France and South Korea and when comparing these plans there are a number of common areas: improving awareness and education, improve early diagnosis and treatment and support at home and in care homes; strengthen support for family caregivers and training of professionals; improve coordination of care; and finally, monitoring progress, commit to research and recognise the role of innovative technologies.

Finally, a movement has started to make communities more dementia friendly with several good initiatives in Asia, Europe and North America, not surprisingly the parts of the world with the largest ageing populations. In South Korea over 120,000 volunteers were trained to support families of people with dementia, and in Japan a 90-minute training course was developed which has been undertaken by over 4 million people. In the UK, this initiative has since been made into their Dementia Friends programme. Cities in Germany, Belgium and the Netherlands declared themselves dementia friendly and created educational programmes for government officers, policemen, shopkeepers and other members of civil society. The city of San Francisco in the USA was the first in the world with a city wide plan on dealing with dementia. ■

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SATURDAY 23 NOVEMBER

ROUND TABLE
ACTIVITIES OF THE CHURCH TO HELP SICK ELDERLY PEOPLE

1. Report on Argentina

H.E. MSGR. AURELIO KÜHN
Prelate Bishop of Deán Funes and Episcopal Head of Pastoral Care in Health in Argentina

Introduction

In today's Church we are witnessing fine signals of hope despite the major fracture between the Gospel and the culture and the abyss between doctrine and practice, between the 'stupidity of teaching', which is brief and circumstantial, and the constant and broad subliminal catechesis that is offered to the world through the MCS.

For this reason, we need a tested faith that trusts in the power of prayer and the Word of God and in the power of charity…the moral miracle of a concrete love, borne witness to by believers, especially in favour of the weakest, the sick and the elderly.

We need a certain hope that 'goes out and throws out nets', as the Church does. Although not always well understood, the Church has always been, and is, near to fallen man, following the example of Christ, the Good Samaritan. This is demonstrated by the various documents of the Church which, starting with the Second Vatican Council, have defended and promoted life, and the innumerable initiatives of Church institutions in favour of the sick, invalids and elderly people.

The Latin American Episcopate engaged in a clear option for life (cf. *Aparecida* 348, 417) and, through pastoral care in health, drew up, after a long process, the valuable 'Guidelines for Pastoral Care in Health in Latin America and the Caribbean' in the light of the document *Aparecida* during the course of the Sixth Latin American and Caribbean Meeting on Pastoral Care in Health which took place in Panama in 2009 (CELAM, *Missionary Disciples in the World of Health. Guidelines for Pastoral Care in Health in Latin America and the Caribbean*, Buenos Aires, 211).

A similar process has been engaged in by the Bishops' Conference of Argentina, as we will see during the course of this report.

The suffering and the emptiness of today's man, who needs and looks for nearness and attention, are real, globalised and very painful. The Church, in each believer, following Christ, the Good Samaritan, seeks to draw near to sick people and to offer them the witness of a concrete love (cf. *Aparecida*, nn. 407-430).

1. Pastoral Care in Health in Argentina

The Church achieves this attentive nearness through pastoral care in health. 'A form of pastoral care that proclaims the God of life and promotes justice and the defence of the rights of the weakest and the sick; which involves the whole of the Christian community in organised and structured work within general pastoral care' ('Guidelines for Pastoral Care in Health in Latin America and the Caribbean', n. 5) .

At a practical level, in 1991 the Bishops' Conference of Argentina established the Bishops' Commission for Pastoral Care in Health which is made up of three bishops, one of which is its president, and a priest who acts as its executive secretary. In 2006 this commission created the Pastoral Support Team which is made up of regional delegates for pastoral care in health.

Starting with this institution, in a coordinated way the service of accompanying, animation and formation in the dioceses was implemented. In each of these a diocesan commission has to be formed that is entrusted with promoting organised pastoral care in health in parishes where the parish groups accompany sick people and the elderly and their families, both in their homes and in institutions.

This is the organisational schema. In practice, each time we have to begin afresh. Each year the Bishops' Commission for Pastoral Care in Health organises five work meetings and after Easter organises a Meeting of the Diocesan Delegates for Pastoral Care in Health which lasts for three days. A fraternal spirit is cultivated at this meeting, experiences are exchanged, information is provided on the situation in each diocese, specific formation is received, the celebration of the National Day of the Sick is organised and regional meetings are planned.

2. Care for the Elderly

At this round table we are especially interested in pastoral care for elderly people, which is also a part of pastoral care in health. 'The lack of integral care and the situation of being abandoned in which elderly people, the mentally ill, patients at the terminal stage of their illnesses and the disabled live is a reason for concern' (*Guidelines*, n. 20).

Elderly people, indeed, constitute an increasingly numerous sector in parish contexts and they need to be provided with special pastoral care by us. The family environment is not sufficient to meet their needs at the level of support, accompanying and care, and even less to help them to live their old age not as an antechamber to death but from the approach of the paschal mystery of Jesus. We need to help them to live this final stage of their lives starting with faith and the wisdom of the cross, with dignity and fullness, still ready to express their capacities and to participate actively in the life of the Church, above all as those who intercede with Christ through prayer and sacrifice that is offered up generously for other people, in particular for their own families. We should equally motivate sick people and elderly people to unite themselves to Christ in their dedication to the salvation of their brethren (cf. *Cristifideles laici*, n. 4).

The CELAM offers a number of guidelines for pastoral care for old age:

– *Pastoral care of presence*: being with the elderly person, comforting him or her, loving him or her, drawing near to his or her reality with a cordial and friendly approach, without a burning wish to evangelise at any price. Knowing his or her world, his or her way of seeing things, and sharing in the good and the bad.

– *Pastoral care that is active and creative*: retrieving the active roles of elderly people, giving them new opportunities to develop, thereby making old age a time of fulfilment and fullness.

The goal here is to bring integral care to elderly people and to undertake activities that involve wellbeing in order to attain a life that is more acceptable and that is more integrated into the community and open to the transcendent dimension and to the final meeting with God (cf. Selare, *Pastorale della Salute, CELAM,* Colombia 1999, pp. 258-260).

In Argentina, when surveying the general panorama, we may highlight the following pastoral activities for elderly people.

Commissions and institutions for pastoral care in health. Not many hospitals belong to the Church – only four. However, the Church is present in state hospitals through the chaplains, some of whom work full time, and through the service performed by volunteers. Inland in the country, at least in some areas, where state hospitals do not have specialised care, old and poor elderly people are admitted to them. The Church is present through numerous Caritas centres, hospices, with many congregations and associations that are totally dedicated to care for the elderly. (cf. the report of the Executive Secretary of the Bishop's Commission that was presented during the meeting of the CELAM: the Bishops' Commission for Pastoral Care in Health).

3. Some Examples of Service for the Elderly

3.1 Drawing near through Radio Maria

Through Radio Maria, which has over a hundred broadcasting stations throughout the country, and through programmes open to dialogue with the general public, we have managed to establish good communications with elderly or sick people and their families. These programmes offer an opportunity to draw near to them and to engage in communication that is often very profound, and to provide positive encouragement that illumines and comforts elderly people or those who do not see a meaning to their lives. Thanks to this instrument, we can reach people, families and places that it is not possible to reach by other routes.

3.2. The emergency priest service

Death can surprise us like a thief, any day and at any time, at home, in a hospital or any other place. Every believer would like at that moment to have the comfort of the grace of God. But today it is not easy, especially in the large cities, to find a door open and a priest available. This is often the case during the day and even more the case during the night.

It was for this reason that in 1952, in Cordoba (Argentina), a member of the laity did not manage to find a priest for his dying father; he thought that just as there was a 'doctor on duty' or a 'pharmacy open' so also there should be a 'priest on duty'. He thus had the insight to create a 'priestly guard' to whom all Christians in painful situations could turn without difficulties and thus obtain a priest for the sacraments or for some other kind of emergency.

There thus began the Emergency Priest Service, as service which began to act for the first time in Argentina in 1952. In a centre, with a telephone number, a priest and two members of the laity waited piously for the call of some brother or sister who was in need of the grace of God.

At the present time the Emergency Priest Service is present in sixteen dioceses, which are some of the most important in the country, and there is a priest and two or three lay volunteers who provide their services free from nine or ten in the evening until six the following morning. The priestly activity that is engaged in, where it is Christ that principally intervenes, and in which the priest participates as a mediator and instrument of the Lord, means that lay people cooperate in salvation and constitute a true lay ministry. This is an expression of charity because these lay people make themselves available to their suffering brothers and sisters.

Today the Emergency Priest Service has its statutes, a directive committee and an ecclesiastical consultant who is approved by the diocesan bishop. The diocesan services are brought together in a fraternal and institutional way through a federation that is recognised by the Bishops' Conference of Argentina.

3.3 Extraordinary ministers of the Eucharist

The lay ministry of the extraordinary minister, which is envisaged in canon 230 of the Code of Canon Law, in addition to service provided in churches also offers the opportunity of a service for elderly people and sick people in their homes and in health-care centres. Integrated into pastoral care in health, the extraordinary ministers of the Eucharist bring Viaticum to the sick and to the elderly as a living presence of the Church within families, a point of reference and of contact with the parish priest, for whom often finds it impossible to meet an elderly person. This is a service that is widespread in the country.

4. Health-care Institutions

4.1. Church institutions

In Argentina, the Church provides numerous services for elderly people in the centres run by Caritas, in hospices of a Christian character which have been established since the year 2002, and in numerous homes for the elderly that are administered by religious Congregations, institutes and associations of members of the laity. In Christian communities a great social sensitivity is discovered as well as true fraternal charity which together make possible the creation of programmes of home care, centres where accommodation and meals are offered to people who are alone or who are passing through, as well as trained assistants, pastoral workers and 'telephones' for adults to whom people can turn at times of loneliness or emergency.

Open hands. Here I am referring to a Christian organisation that is open to all men and women of good will who, through voluntary work, have the mission of serving, aiding and honouring those who individuals who are most in need.

Here one is dealing with an option for voluntary work that offers an opportunity to help those who wish to share resources, ideas and time to provide service, hands to bring help and smiles to bring happiness, creating areas of trust, joy and hope (cf. WWW.fundmanosabiertas.org.ar).

The grandparents of Jesus. This is the St. Joachim and St. Anna Association of the Faithful of Cordoba whose charism is service both for elderly people for their rehabilitation as people and for their families, giving them the clear sensation that they are people who are loved, cared for and respected, quite apart from the circumstances in which they have had to live.

The members of this association bring to it a lay lifestyle and not a religious one. Amongst them there are consecrated men and women, missionaries, family relatives who accompany the missionaries, members who are co-workers, young members and voluntary workers. These are new charisms that have arisen within the Church to serve the most marginalised (cf. www.losabuelosdejesus.org.ar).

These are only some examples that demonstrate the life of the Church as a servant to those most in need. It is certainly the case that many religious Congregations could offer other examples of this.

4.2. State institutions

The state also performs a role in providing care to elderly people. It makes available numerous resources in this field (PAMI: Programme for Integral Medical Care) and has specialist centres for providing elderly people with care, with a very active presence of Catholic voluntary workers, as is the case for example with the J.J. Puente Hospital in the prelature of Deán Funes. In this rural area of the Province of Cordoba, as well, there are small hospitals which also act as homes for elderly people who live alone or who are isolated in the countryside. This is a service that is present throughout Argentina.

5. Other Services

5.1 Elderly people who come together to pray and to be near to each other

This is a personal pastoral experience in small and open communities where elderly people who are near to each other and who cannot go to Church meet together in small groups, rotating their homes as locations for these meetings, in order to say the rosary, share the Word of God and receive holy communion when the presence of a priest is possible: a fraternal meeting that becomes a celebration of the Eucharist.

5.2 The 'Holding my Grandfather by the Hand' Project (cf. Project)

This is the project of a grandmother who wants to facilitate the active participation of elderly people who are grandparents and open up spaces of dialogue and channels of communication between grandparents and their grandchildren in order to achieve their mutual enrichment. One is dealing here with an 'emotional dialogue' that includes the exchange of emotions, affection, values, habits and rules etc. This project is proposed so that it can be implemented through various study groups during the school and catechetic years.

5.3. Pastoral care provided by porters

I am referring here to an initiative in the city of Buenos Aires. The porters in blocks in large cities know about, and have access to, flats and the people who live in them, many of whom are elderly people and often live alone. Porters, therefore, can be necessary and useful mediators for pastoral workers.

For this reason, in Buenos Aires there has been the initiative of bringing together porters at pastoral meetings, generating in them awareness of being able to provide a service for sick people, the elderly and people who live on their own, and motivating them to adopt a pastoral and spiritual approach that involves mediation between pastoral workers and sick people so as to become pastoral workers themselves.

5.4 'Red Sanar'

For sixteen years a network has existed in the country known as 'Red Sanar'. Created as a self-help group to address the phenomenon of a wave of suicides that was taking place amongst teenagers, this has become a supportive and free non-governmental organisation which engages in prevention and therapy as regards disturbances caused by worry, anxiety, stress, phobias, panic attacks, compulsive disturbances and depression. It does this through the generous contribution of voluntary workers, many of whom have themselves been helped in this area by taking part in the laboratories of the network. These disturbances today constitute an alarming phenomenon which attacks people and their realities. In Argentina there are sixty agencies of this network and many elderly people belong to them.

6. Voluntary Work as a Practical Expression of the Love of God

Legislation on voluntary work exists but this is an area that is not regulated. Very many volunteers freely offer their time, their abilities and even money to help those who are in need. Their mission is to serve, to help and to give dignity to those most in need, improving through voluntary work their quality of life and alleviating the situations of pain and of lack that they suffer from. These volunteers work in many areas of society and within the Church: in Caritas, in parish catechesis and in a special way in the world of hospitals, in old people's homes, and in visiting and accompanying sick people and elderly people.

7. Conclusion

It is certainly the case that care for elderly people, whose numbers and sufferings increase day by day, is not optimal. But we should not fail to recognise the work of the Church which, through the voluntary service of the faithful, priests and consecrated men and women, is near to elderly people and accompanies them. We should appreciate this service, give praise for it and thank the Lord for this work. ■

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2. Sick Elderly People: the Action of the Church in Australia

H.E. MSGR.
DONALD SPROXTON
Auxiliary Bishop of Perth,
Bishop Responsible for
Pastoral Care in Health in
Australia

Your Excellencies, Reverend Fathers, Brothers and Sisters in Christ, it is a joy to be with you today to talk about the action of the Church for sick elderly people. I also wish to recognise the presence today of Rowena McNally, the chair of the Stewardship Board of Catholic Health Australia, who has joined us for these important deliberations, as well as Professor Fran McInerny and Professor Michelle Campbell from Australian Catholic University.

Speaking in this great city last November, Pope Benedict XVI told residents at a residential aged care home that "the quality of a society or civilisation can be judged by how it treats the elderly". When we consider that alongside the mandate that Jesus gives the apostles – "Preach the Gospel and heal the sick", one would struggle to find a group of people more worthy of the Church's love and care than older people who are in poor health.

That is why the Church places such an emphasis on the care – physical, psychological and spiritual – of people in the later years of life. While hospitals affiliated with a range of faiths, or none, can provide high-quality physical care for older people, the Church provides the sort of holistic care that nourishes the body as well as the soul.

The most obvious way that the Church is able to do that is through the provision of pastoral care, thanks to the generous efforts of people in parishes across the country. The ministry of priests and deacons continues to be a vital help to the aged who long for the strength of the Sacraments. As the

Church adapts to a smaller pool of priests, lay people have been willing to assist in the sharing of Holy Communion with people who are unable to attend Mass because of an illness.

Parish communities have been successful in engaging with the aged care hospitals to offer social activities for their residents. In this way, former parishioners remain connected to their home parish, as well as with their families and friends. A growing need for home visits to lonely housebound parishioners is being met by members of the St. Vincent de Paul Society.

Several of our Secondary Schools have worked with aged care institutions in their local areas to create programs of community service for their students. These provide opportunities for the students to visit, especially those in care who do not receive any visitors, and to spend a reasonable amount of time with some residents reading to them and listening to the stories about their lives they are very ready to relate. The students benefit from engaging with the elderly from a human point of view as there are many of our young people who do not have grandparents.

The Catholic Church throughout the world has long been a leading provider of care for older people, through our hospitals and aged care services. In the Australian context, we have a population of about 22 million and the Catholic portion is around 5 million. The Australian government has set its planning for an increase of places for elderly people in aged care facilities from 25 to 113 per 1,000. With one in 10 Australians around the country in a hospital bed or an aged care bed lucky enough to be cared for by a Catholic service – a service inspired by the story of the Good Samaritan – they know they are in safe hands medically, but also in compassionate hands.

I have been fortunate enough to see that first hand in the care that the Little Sisters of the Poor are giving to my father as his health necessitated his entry into residential aged care. The provision of aged care in the Church can be something of an abstract concept for so many of us; this experience of seeing the loving care that Catholic services offer has made it very real for me.

For many older people, though, moving into a residential aged facility – despite needing some assistance – is not an option they are ready to take. Across Australia, Catholic services are responding to the wishes of our clients and providing health care and other forms of care in their own homes.

Recent legislation passed by the previous Government will see a dramatic increase in the number of people who are able to take advantage of the physical and psychological benefits of staying in their own home without forgoing the important care they need. It was a model Pope Benedict himself promoted last year, calling on families and society as a whole to help older people continue to live at home. Home care packages developed by our Catholic health services prolong an elderly person's ability to live at home by providing assistance in showering and general hygiene, house cleaning, physiotherapy and occupational therapy.

Catholic agencies are also mindful of the importance of helping older people, even those who are unwell, live as full a life as is possible. There are many innovative programs around the country, including a program that is considered a national leader.

Southern Cross Care Victoria's Imagine Fund has allowed staff working with older people to recognise opportunities to give residents a positive experience – reuniting with families, a trip to the theatre or a football game, computer training – and help them retain meaning in their lives. This is a particularly important for residents in the service who are isolated from their family or do not have the financial means to enjoy such activities. Age and poor health do not stifle people's interest, their hopes and their aspirations, and physical health can benefit from the emotional advantages of engaging in the sorts of activities people have loved all their lives.

The Church in Australia is also playing a role in shaping the future of care for older people through our Catholic universities, with tomorrow's nurses being trained and formed at the Australian Catholic University, and Colleges of Medicine and Nursing at the University of Notre Dame, Australia, preparing health professionals for the demands of health care in the context of an ageing population.

But there are also more organic training methods taking place. One of our Catholic aged care services, which like so many others has an increasingly culturally diverse workforce, has seen the opportunity for their staff to share their experience and teach some skills to people in their home countries when they travel back for family or cultural events. They return to their homeland with gifts from Australia, but also with expertise that can benefit those working in aged care.

Our universities are also collaborating with Catholic Health Australia to assist in the ongoing development of nurses working in health and aged care, and in the creation of partnerships with Catholic services, to sharpen the focus on how the demographic changes taking place in the West are creating a high demand for aged care and caring for the health of older Australians. Professor McInerny's work as the first Chair in Aged Care – a joint initiative of Mercy Health and Australian Catholic University – is one example of the priority that is rightly being given to this area of work.

With Australia's ageing population set to double over the next forty years, Professor McInerny will drive innovation, provide leadership and establish a long-term vision for the way Australia cares for older people. She will do so by working with twenty other organisations all working towards the same goal of better, more focussed care for older people who need such health and aged care.

While our universities are obviously great places for research into care for older people, just a couple of months ago, at the Catholic Health Australia national conference, we were able to recognise the groundbreaking research of St Vincent's Hospital in Melbourne in the area of the effect of anaesthesia and surgery on older patients living with memory loss. Obviously much has already been said at this conference about the important work being done to help people living dementia and related conditions, but the soaring rates of memory-related conditions mean that much effort must be put into this work. In Australia, dementia has now been listed as a national health priority.

Again quoting Pope Benedict, "One who makes room for the elderly, makes room for life. One who welcomes the elderly welcomes life." In a world that can sometimes devalue or even disrespect the place of older people, the Church must continue to provide the example of what it means to make room for the elderly, to welcome them and to welcome life. ■

3. The Action of the Church for Sick Elderly People

H.E. MSGR. WILLIAM T. MCGRATTAN
Auxiliary Bishop of the Archdiocese of Toronto, Bishop Responsible for Pastoral Care in Health in Canada

Introduction: The Canadian Context of Pastoral Care for Sick Elderly People

Health care in Canada for the sick elderly person has received increased attention due in part to our aging population and the growing knowledge base that has evolved concerning disease, prevention, therapy and treatments for those social and physical illnesses which afflict the aged. This is a general trend in most European, North American and western societies.

In Canada we have a coordinated national/provincial healthcare program where the access to care remains a fundamental human and communitarian right that receives public government funding in which Catholic health care facilities participate. The stewardship and governance of these Catholic institutions requires not only civil and financial accountability but more importantly an ethical responsibility in accordance with the guidelines of the Catholic Health Alliance of Canada – Health Care Ethics Guide[1] which is approved by the Canadian Conference of Catholic Bishops (CCCB).

Catholic health and social service organizations have a particular identity and mission in our civil Canadian society. The service which they offer is first and foremost understood as "ministry" because it is motivated by the gospel and is rooted in a Catholic faith tradition. It upholds the unique dignity of the individual and the interconnectedness of all people by promoting the sharing of communal goods in society. This vision challenges all systems of healthcare to uphold those values for all people and especially for the sick elderly person while at the same time inviting those engaged in this ministry to create a community of compassionate care.

Meeting the needs of individuals through all stages of life is part of the mission of Catholic health care. Serving the elderly and those who are chronically ill is an essential part of that ministry. There are approximately 110 Catholic-sponsored health organizations in Canada. They provide a broad spectrum of professional services as part of their elder care programs including acute and primary care, nursing home, medical and day care, home health, senior housing, assisted living, respite and palliative care and counseling. This focus is one important expression within our local churches of the healing ministry of Jesus Christ.

The social organization of healthcare in Canada is evolving. The shift in focus from acute care hospitals to outpatient surgery centers, ambulatory care, nursing homes, and long term care centers is expanding. This is due to the inflation of healthcare costs and to efforts to reduce the time required for hospitalization after surgery and for acutely ill patients, but also because it is therapeutically and ethically better not to disrupt the normal life of patients. The elderly in accessing healthcare are naturally relieved of many ordinary social obligations yet they also need to be helped to see sickness and aging as part of the continuum of life and not as an interruption in living.[2]

In western society our concept of human living is influenced by strong cultural factors which extol healthy living environments, diet and exercise as ways to maintain youthfulness. However these same values may negatively impact our concept of aging and care for elderly people who could easily become stigmatized and made to feel that they are a growing burden to society. At the same time new knowledge and understanding in healthcare services have been advanced through medical research, the human and social sciences and technology to improve treatments for illnesses and to enhance the overall health status of the elderly person. Genetic, and stem cell research are being pursued in the hope of finding creative solutions to help alleviate human suffering and to offer reparative therapies for particular groups and society as a whole including neurodegenerative diseases such as Alzheimer's and dementia that affect mainly the elderly.

Hospitals and nursing homes in which elderly patients can remain for long periods of time are now coming under increasing social and ethical critique. The sick elderly person, their caregivers, doctors and nurses and family members increasingly face decisions of continuing or withdrawing treatment and most elderly people express the desire to die with dignity and with appropriate palliative care are.

As you can see the context of healthcare service and the challenges facing the Canadian Church in caring for the sick elderly person is not very different from other western societies, however, I would like to offer some specific reflections in how we are trying to respond to them and at the same time witnessing to the tradition of Catholic healthcare.

1. Challenges and Responses

1.1 Advocacy

In Canada national statistics indicate that the number of seniors will increase from 4.2 million to 9.8 million between the years 2005 and 2036 while currently those above the age of 76 are the fastest growing age group in the country.[3] In facing this reality, Canadian Catholic healthcare and social services are being challenged to assume greater social responsibility for our aging population. They serve and advocate for those in social conditions which place them at the margins of society and make them particularly vulnerable to discrimination. More and more they are being asked to recognize the importance of education and advocacy as part of their mission. This involves education in health promotion and disease prevention for the elderly but also engagement in a dialogue and ongoing reflection on the Christian meaning of suffering, illness, health, morality, life and death.

The increasing life expectancy of our aging population in Canada and the growing percentage of elderly people have heightened issues of resource allocation, distribution of public funds, the planning and the re-organization of programs and services in caring for the elderly. The introduction of legislation by one province to allow the service of what it terms "medical-aid-in-dying" is in fact synonymous with euthanasia and assisted suicide. The perpetuation of confused language and concepts needs to be addressed through education, research, and the advocacy of other alternative care, such as palliative care and hospice for the sick elderly person who is in the dying stage.

In Canada we are fortunate to have three Catholic advocacy groups which are engaged in distinct but complementary research and education to deal with issues of life, the family, healthcare, medicine and bioethics. They are the Catholic Health Alliance of Canada (CHAC),[4] the Catholic Organization for Life and Family (COLF)[5] which is co-sponsored by the Canadian Conference of Catholic Bishops, and the Supreme Council of the Knights of Columbus and the Canadian Catholic Bioethics Institute (CCBI).[6]

1.2 Community Healthcare and Social Services

There has been a shift in the healthcare delivery model within Canada. It has become one of "integration" which requires greater collaboration among healthcare institutions for the delivery of care programs and the coordinated interaction with social service agencies, not to mention other sectors of society such as education, housing, religious groups and healthcare professionals. The breadth of Catholic identity and mission for our healthcare institutions can become challenged in these expanding relationships. However, it is also an opportunity to strengthen our witness in society while ensuring fidelity to the healing mission of Christ.

There is a growing demand for community based healthcare programs. This has a positive value in that we are finding ways for the sick elderly person to retain contact with the life they were experiencing prior to illness, e.g. family, community and religion, while receiving care in their homes. This has proven beneficial for the entire well-being of the person, not only physically but more importantly in their spiritual care.

The living conditions of the elderly person in providing post-discharge care from acute health care facilities is becoming an increasing problem. The number of elderly living in poverty has grown in our Canadian society and this remains a negative social determinant for ongoing health risks. The lack of immediate family and social relationships to support the elderly puts at risk many people who cannot care for themselves after neurodegenerative diseases take hold, i.e. dementia, Parkinson's, etc. It is also essential that the elderly genuinely participate in the decisions which affect their lives, in terms of care and access to services, either as an individual given their mental and physical capacity or through advanced health care directives made by a legally appointed decision maker.

The Church's response to serving the sick elderly person in this integration model of healthcare is evolving. At the level of institutional collaboration with social service agencies we are witnessing the sponsorship of palliative care and outreach programs of therapy in the home, caregiver support, socialization groups and visiting to those suffering from mental illness including the elderly. It is also reflected in new initiatives in our parishes e.g. parish nurses, lay-led programs of visitation, spirituality and prayer, and the communal celebration of the Sacrament of the Sick for the elderly, etc.

1.3 End of Life Care and Decision-making

There is a growing ethical debate in sectors of Canadian society around the moral and legal issues associated with the "right to end-of-life care" now being proposed. In Canada at present we do not have legalized euthanasia and assisted suicide. The decisions which a patient and or their family face are normally ones of continuing or discontinuing medical treatments such as ventilation and the suctioning of lungs, artificial feeding and hydration, or treatments for recurring infections which weaken the patient. Often at the end stage of neurological disorders the elderly person cannot or will not swallow safely …what is the most compassionate way to care for them? The issue of pain management and the use of medication to relieve pain and provide comfort, especially at end-of-life, have become important.

In a most recent Supreme Court Case the role and right of the physician vs. the family to determine if a patient should continue on ICU "life support" rather than palliative care was decided. The Supreme Court has ruled that life support can be discontinued only with the consent of the patient or the substitute decision maker (SDM). It did not explore the question that at certain stages the provision of some treatments may be futile and may impact negatively on the patient.

The role of the Church in providing ethical consultation and spiritual counseling to patients and their families is becoming critical. It is important to embrace life as gift, but also to embrace the end of life and provide assistance to those who accompany the dying.[7] This is provided in acute care Catholic health facilities through trained chaplains and ethicists, but the focus needs to shift to the community and the parish. It is critical for the Church to provide workshops and information sessions around care of persons at the end of life, medically assisted nutrition and hydration, cardiopulmonary resuscitation, refusing and stopping treatment, palliative care, decision making and the dying person, and advance care planning.

1.4 Stem Cell Research

Research involving humans continues to increase in breadth and intensity and provides significant benefits for the human community. The findings of this research can offer creative solutions and hope for individuals, for particular groups and for society as a whole. The manner in which the research is conducted must always respect the dignity and integrity of persons involved and to serve the common good.

In Canada, stem cell research for neurological disorders and to minimize the effects of aging for the elderly has become a current issue of medical research. Our Catholic tradition encourages us to participate in research as way of being in solidarity with others and which reflects our being rooted in charity. The selection of certain ethnic and cultural groups of people to participate in these research initiatives is being more widely advertised and promoted in our urban cities. (E.g. Chinese, Asian, etc.)

Stem cell research holds promise of correcting numerous disease situations. There are various sources reported from which stem cells may be derived (e.g. human embryos, human umbilical cord and adult stem cells). Research using stem cells that do not involve the use and destruction of the human embryo is permissible.[8]

The Church is often called upon to voice its moral teaching on issues related to medical research and stem cell therapies. The need for laity and clergy to be adequately trained and formed to provide this teaching and witness is critical. The accompaniment and support of medical professionals, nurses and health care workers on the part of the local church is very important as new knowledge and understanding in health care, treatments and technology evolve and specifically impact on those involved in geriatric healthcare and services.

1.5 Healthcare Planning and Spiritual Care

The increasing percentage of elderly persons in our society and the degenerative problems which this population faces have heightened the need for healthcare planning, stewardship and allocation of resources according to an "integrated model" of delivering services. However, beyond simply dealing with this present and impending financial demand on the Canadian healthcare system there is an opportunity to address preventive issues which contribute to healthcare needs in our society.

There have been advances in preventive medicine and these are being expanded to see the correlation of environmental social determinants that affect our health and well-being and which start early in life. The determinants of health include – education, shelter, medical care, wealth, and personal lifestyle (e.g. diet, exercise, etc.). Research, education and advocacy are directed to that segment of the population which is aging and is elderly in the hope that the knowledge of these health determinants can assist the physical effects they are facing.

The planning of spiritual care by specific ministry for maturing adults in our parishes and communities is one potential response of the local Church. This would address the growing number of elderly in our parishes but would also focus on those spiritual determinants of the maturing adult through such ministry with outreach to these individuals in the parish. Workshops, retreats on topics on health, aging and spirituality could be a means of evangelization to the elderly in the later stages of their Christian journey.

Conclusion

In the introduction to the *Canadian Catholic Health Ethics Guide* it states that the "Good Samaritan (parable) challenges Catholic health and social services explicitly to respect dignity, foster trust in care and promote just health systems".[9] This vision and response found within the Gospel must continue to guide and motivate us in the care of the sick elderly person. It will also allow us to respond with authenticity in carrying out the healing ministry of Jesus Christ in the face of the many complex social and ethical questions faced by the aged and elderly in our Canadian society and in the world.

Notes

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4. India: Sick Elderly People with Neurodegenerative Illnesses and Mental Disorders. Emerging Challenges and the Way Forward for the Church

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Introduction

By 2050 in India, due to technological advancement in health care, the elderly segment of the population aged 60 years will surpass the population of children below 14 years.[1] In absolute terms India had more than 91.6 million elderly in 2010 with an annual addition of 2.5 million elderly between 2005 and 2010, which is projected to reach 158.7 million in 2025.[2] The increasing number of sick elderly people suffering from neurodegenerative illnesses like dementia and mental disorders like depression is a part of this process. By 2050, India will have 43 million people aged 80 or over.[3] The situation becomes all the more challenging because 80% of the elderly are in rural areas, 30% of the elderly are below the poverty line, and healthcare costs are rising.[4] As per Global Age Watch Index (GAWI), India ranks 73rd out of the 91 countries sampled.[5]

The message of Pope Francis, on the occasion of XXI Plenary Assembly of the Pontifical Council for the Family, is significant in this context, "Children and the elderly are the two poles of life and also the most vulnerable, often the most forgotten. A society that abandons children and marginalizes the elderly severs its roots and obscures its future. Whenever a child is abandoned and an old person is marginalized, this is not just an act of injustice, but also demonstrates the failure of that society. Taking care of children and the elderly is the only choice of civilization."[6]

This paper gives an overview of what is the status of the elderly in India, especially those who are affected with neurodegenerative illnesses and mental disorders. This paper also gives a special emphasis on the socially and economically marginalized/excluded and vulnerable (women) among the elderly; the emerging challenges for the elderly and for those involved in geriatric care; how the Church in India responds to the situation; and lastly, a way forward for the Church in India.

1. The Elderly – the Indian Scenario

The 'National Policy on Older Persons' adopted by the Government of India in January 1999 defines a 'senior citizen' or an 'elderly' person as a person who is of age 60 years or above. Nearly 7.5% of India's population is presently aged 60 years and above[7]. It is projected to rise to 12.4% of population by the year 2026.[8] By 2050, pursuing the existing trend of longer longevity than men, women over 60 years will exceed the number of elderly men by 18.4 million.

About 65 per cent of the aged have to depend on others for their day-to-day maintenance. Of these, 70% are women.[9] Nearly 40% of persons aged 60 years and above (60% of men and 19% of women) are working. In urban areas only 39% of elderly men and about 7% of elderly women are economically active. In contrast, it is 66% and 23% respectively in rural areas.[10]

As per HelpAge India, 52% of India's oldest old (80 +) are either in a poor or a very poor health condition; 80% reported non-availability of support system at a community level. 12% of the oldest old are still engaged in economic activities.[11]

31% of older persons reported facing abuse (material exploitation, financial deprivation, property grabbing, abandonment, verbal humiliation, and emotional and psychological torment).[12] Most of the cases go unreported in the name of family honor and victims are afraid of losing even the minimal support they receive.

2. Provisions for the Elderly in India

Article 41 of the Constitution assures public assistance in old age. National Policy on Older Persons (NPOP) 1999 envisages State support for the elderly. The enactment of the Maintenance and Welfare of Parents and Senior Citizens Act 2007 is to ensure need based maintenance for parents and senior citizens and their welfare. The government through the Central Sector Scheme of Integrated Programme for Older Persons (IPOP) encourages Public Private Partnership – supporting non-state actors to maintain/ organize various facilities for the elderly. The other measures are old age pensions, income tax exemption/deduction, travel concessions, geriatric departments in medical colleges; two National Institutes on Ageing at Delhi and Chennai, etc.

Many of these measures however are not fully implemented. Recently, the National Policy on Senior Citizens 2011, and in line with it, the 12th five year plan and National Mental Health Programme, give special emphasis to senior citizens suffering from severely disabling diseases. This includes various types of dementias including Alzheimer's, Parkinson's disease, depression and other psycho-geriatric disorders. On the whole, the country is yet to put measures in place to effectively meet the impending scenario of the growing population of the elderly, especially those suffering from neurodegenerative illnesses and mental disorders.

3. Elderly People with Neurodegenerative Illnesses and Depression

The increased numbers of the sick elderly with neurodegenerative illnesses and various mental disorders will have a marked impact on India's infrastructures and healthcare systems, which are at present ill prepared in many regions. About 64 per thousand of elderly persons in rural areas and 55 per thousand in urban areas suffer from one or more disabilities.[13]

As per the Ministry of Health and Family Welfare, 1 in every 4 among India's elderly population are depressed, 1 in 3 suffer from arthritis while 1 in 5 cannot hear. While 1 in 3 suffer from hypertension in India, almost half have poor vision. Around 1 in 10 experience a fall that results in fracture while 2 in 5 are anemic.[14]

As per HelpAge India, 30 million are lonely and 1 in every 8 elderly feels no one cares they exist and 90% have to continue to work if they have to survive.[15] 88% said loneliness can lead to physical and mental ailments like depression.[16] The research suggests that suffering from depression can significantly increase the chances of developing dementia/ Alzheimer's disease later in life. In 2010, it is estimated that there are 3.7 million people affected by dementia (Alzheimer's disease, AD and vascular dementia, VaD) in India, and the total societal cost is about Rs.1,470 million. People with Dementia (PwD) are expected to double by 2030, increasing the cost by three times.[17]

3.1 Care for the Elderly with Neurodegenerative Illness – Challenges

At present, the sick elderly with depression and neurodegenerative illnesses are taken care of mainly by their families with not much support from the public healthcare system, even at a primary care level. The joint family system — the traditional support system for sick and dependent elderly people – is crumbling because of the migration of the younger generation to the cities in search of better prospects. The advent of nuclear families also adds the woes. The women who traditionally took on the role of caregivers are also working and cannot spend as much time caring for the elderly.[18]

Neurodegenerative conditions like dementia are considered a normal part of ageing and are not perceived as requiring medical care. Thus primary healthcare physicians rarely see this condition in their clinical work. Private medical care is preferred and this leads to a higher out-of-pocket expenditure for care. Caregivers experience significant burdens and health strain. More than 80% of caregivers are females and around 50% are spouses who are themselves quite old. Most of the old-age homes do not admit people with dementia. The stigma of aging, arising out of neurodegenerative illness like dementia, depression, incontinence, etc., is another social barrier to access to health by the elderly. People with dementia and other types of neurodegenerative illnesses and mental disorders are often neglected, ridiculed and abused.[19]

3.2. Common Barriers to Health for the Elderly – Accessibility and Affordability

The key barriers to access to health for the Indian elderly include social barriers shaped by gender and other axes of social inequality (religion, caste, socio-economic status and stigma). The physical barrier of reduced mobility declines their social engagement and limits the reach of the health system. Health affordability constraints include limitations in income, employment, assets and the meager financial protection offered in the Indian health system.[20]

Social security coverage, such

as, employer insurance, pension scheme, etc., covers only a negligible segment of the employed population in organized sectors. The majority of the workforce are engaged either in the unorganized sector or self-employed. They are not entitled to formal retirement benefits. As a result, a considerable proportion of the elderly are forced to earn their living by engaging in some work to carry on with their lives.

As 83% of healthcare expenses are private out-of-pocket expenditures,[21] the deprivation is severe and crushing for the elderly for whom the need for healthcare increases with age. Even where the care is physically accessible, costs of accessing this care becomes beyond their reach. For the willing caregivers, especially those struggling to make both ends meet, the sick elderly becomes a severe economic burden. The growing commercialization of healthcare and the deficiencies in the public health care system also makes the situation more complex.

Among the elderly, women suffer the most – especially widows (due to mobility, employment, property, and financial constraints). The predicament of elderly women is aggravated by a lifetime of gender-based discrimination. Ageing women are more likely to get excluded from social security schemes due to lower literacy and awareness levels.[22]

4. The Indian Church in the Health Sector

The Church in India, in line with the vision statement of her health policy, firmly upholds the mandate from Jesus Christ, the Divine Healer, to ensure life in its fullness, and inspired by his compassionate love, envisages a healthy society where people, especially the poor and marginalized, attain and maintain holistic well-being and live in harmony with the Creator, with themselves, with one another and with the environment.[23] Even though the Catholic population of the country is less than 1.5 percent, the Church in India is engaged in various services: 746 small, medium and major hospitals, 2,574 health centres, 107 centres for mental health centres, 61 centres for alternative systems of medicine, 162 non-formal health facilities,165 leprosy centres and 6 medical colleges.[24] There are 615 residential health care centres for the aged. Along with these, there are 678 training centres, and 443 rehabilitation centres are involved in the preventive and curative care of the people, which includes the elderly and persons with disabilities.[25] There are 120 nursing schools/colleges, 123 community care centres for people living with HIV/AIDS, including 40 centres for infected/affected children and 60 counselling centres and 82 centres for tuberculosis or the terminally ill (palliative care centres).[26] These apart, there are almost 600 institutions that are project-based. They are focused on certain illnesses in collaboration with the government and are also engaged in other social concerns.[27]

One can safely assume that a nearly 0.13 million persons render services in these institutions, consisting of religious, lay workers and volunteers, taking all the facilities together. Congregations for women religious and dioceses are engaged in offering medical services, with the contribution of the former being much larger. The medical services consist not only of treatment or surgical interventions but also counselling, conducting camps, awareness and outreach programmes.

4.1. The Catholic Health Association of India (CHAI)

As one of the main arms of the Health Commission under the Bishops' Conference, the Catholic Health Association of India (CHAI), founded in 1943 by Sr. Dr. Mary Glowrey, an Australian nun, is the largest network of nearly 3,412 Catholic healthcare institutions in the country. 84% of them are located in medically underserved areas operating through diocesan and 11 Regional Units across the country. CHAI's member institutions carry out varied services: 2,263 primary care centres, 417 secondary care hospitals, 183 tertiary care hospitals, 5 medical colleges, 18 hospitals offering DNB, 120 nursing schools/colleges, 82 terminal/palliative care centers, 103 mental health centers, 123 HIV/AIDS community care centers, 32 counseling and de-addiction centers, 250 training institutions, 210 disability rehabilitation centers, 121 geriatric care centers and 52 leper hospitals.[28]

This network, with over 1000 sister-doctors, 25,000 sister-nurses and 10,000 plus religious paraprofessionals, has been rendering critical health care services to the poor and marginalized – yearly reaching out to more than 21 million. This includes 5,000 HIV patients per day, around 2,000 children affected or infected with HIV being provided institutional care, 15,000 taken care of under community based care, and 10,000 children with special needs provided with educational, health and rehabilitation support annually. CHAI member institutions facilitate more than 2 million Self Help Group Members. Over 5,000 nursing students graduate every year from CHAI member nursing schools.

5. The Health Policy of the Catholic Church in India and Care of the Elderly

The health policy of the Catholic Church in India recognizes that the elderly have special needs that should be addressed at the individual, group, family and community levels. Catholic healthcare facilities will increasingly get involved in care for the elderly and also work towards creating an enabling environment for them within their own families. The core strategies are to have geriatric departments in the tertiary care system and geriatric services in other health institutions and ensure priority for the elderly in health care facilities with care and compassion. And also to maintain counseling services and linkages with other institutions to deal with the psychological and social needs of the elderly. The priests, religious sisters and others work with families to ensure that the family environment is conducive for the elderly. Palliative care in hospitals and care homes prepares the elderly for a graceful old age and the final moment of life, and protects the dignity of the dying person. The families and caregivers are made to understand and accept the needs of the elderly and to support them with gratitude and respect and children should take care of their ageing and sick parents. Emphasis is also given to the training of health personnel in geriatric and palliative care and counseling.[29]

5.1. The Action of the Indian Church for the Elderly

All over India, the Church has 615 homes for the aged, taking care free of cost of nearly 18,500 elderly people who are mostly sick and abandoned by their families. However, most of these homes are located in middle-income level southern States, with nearly 40% located in the State of Kerala, followed by Karnataka, Maharashtra, Goa and West Bengal.[30] The Church is rendering service to more than 60,000 elderly people on a daily basis, including around 18,500 in its homes for the aged and 1,700 in its palliative care units. This does not include the elderly supported in its project based institutions/organizations and those contacted daily while doing home visits as part of pastoral care. Of late, serious efforts have been made to train nurses and other frontline health workers in geriatric care.

Compelled by Jesus' love and his preferential option for the poor and marginalized, Church health institutions fulfil their obligations to continue and strengthen their services for the economically underprivileged and socially excluded and vulnerable – the elderly, children and women – and extend them to more medically underserved areas. The emerging challenges and threats from not-so-friendly external factors – whether technical/professional, new legislation, social, economical and political – call for serious introspection. The Church has to face the lethargic, often corrupt, public and prohibitively profit-minded private healthcare system.

6. A Suggested Way Forward

In spite of all the commendable efforts much needs to be done regarding the care of the elderly in India. The Church, under the aegis of the Catholic Bishops' Conference of India, needs to leverage the full potential of healthcare networks like the Catholic Health Association of India and of other Christian denominations and Civil Society Organizations. *The Church also needs to do advocacy in the following areas*: 1. for the recognition of neurodegenerative illnesses like dementia, depression and other mental disorders, especially affecting the elderly, as components of the primary healthcare package of the country; 2. for the availability of essential drugs for the treatment of the sick elderly with neurodegenerative illnesses and mental disorders at affordable cost; and for the legalization of nursing practitioners.

Other areas where the Church needs to act are sensitization, training and research: 1. Sensitizing and educating the public against stigma and discrimination in relation to the sick elderly; 2. creating awareness among the elderly, caregivers, elders and youth at a community level in the National Policy on Older Persons, legislation like 'The Maintenance and Welfare of Parents and Senior Citizens Act 2007', and various schemes benefitting the elderly; 3. providing refresher training to primary care physicians to attend to sick elderly suffering from neurodegenerative illnesses, depression and other mental disorders; 4. promoting the significance of 'task-shifting' by involving Accredited Social Health Activists (ASHAs), trained birth attendants (Dais) and other frontline health workers under the National Rural Health Mission, successful lay/barefoot counselors caring for young people at risk in many organizations, etc. and making care for the sick elderly and mental healthcare more accessible and affordable; 5. training and supporting caregivers/family members to provide home-based care as far as possible to the elderly, especially those suffering from neurodegenerative illnesses and mental disorders; 6. promoting the utilization of modern technology – for instance, telemedicine – and training frontline health workers to handle them, thereby making quality healthcare to the elderly more accessible and affordable, especially in rural and vulnerable areas; and 7. promoting and undertaking research in the field of geriatric care to make it more evidence-based, accessible and affordable for the marginalized/excluded and vulnerable among the elderly.

Inculcating the culture of "involving all" in Christ's healing ministry, the Church in India has to facilitate the building of local ownership and Caring Communities supporting the elderly towards healthy ageing with dignity and self-respect. The endeavor should be undertaken by the elderly themselves, caregivers, community/religious leaders, PRIs, young people, teachers, professionals, frontline health workers/volunteers, etc. As a part of this, the Church has to facilitate the democratization[31] and decentralization of medical knowledge. This calls for the empowerment of local communities with information and skills to organize, demand and access the rights and entitlements from the perspective of health as a fundamental right, with a special emphasis on the elderly, children and women. ■

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5. The Experience of the Church in Poland

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Illness and old age, notwithstanding the undeniable advances of medical science, remain a shared experience of existence that is inseparably linked to the human condition. In today’s world elderly people are treated as a burden and an obstacle for young people. This generates a sense of insecurity, of frustration, and a lack of gratitude and benevolence. The weakness of contemporary social security means that elderly people, by no means rarely, live disadvantaged economic conditions.[1]

1. The Culture of Waste and its Consequences

The above-mentioned situation facilitates the creation of what in the view of Pope Francis one could call ‘the culture of waste’, which has penetrated the mentality and the attitudes of contemporary man. The Holy Father observed that ‘If a computer breaks it is a tragedy, but poverty, the needs and dramas of so many people end up being considered normal.... In this way people are thrown aside as if they were trash...what dominates are the dynamics of an economy and a finance that are lacking in ethics. It is no longer man who commands, but money, money, cash commands...Nevertheless men and women are sacrificed to the idols of profit and consumption: it is the “culture of waste”’.[2]

This attitude fosters the loss of sensitivity towards man, in particular if sick and elderly. According to this logic, to invest in elderly people, who have reached the threshold of death, constitutes acting against budgets inasmuch as it can cause financial damage; it is pointless because it does not produce useful material effects;

and in addition it is even injurious because it is perceived almost as an abuse of power to the disadvantage of the young. Illness, which is even more damaging for budgets, becomes a subsequent cause of throwing away.

2. The Tasks of the Church in Relation to Sick and Elderly People

Within the context of the Christian approach to illness and old age one can formulate a number of suggestions for pastoral care.

First, the role of the Church must follow an unceasing promotion and defence of the dignity of man from the moment of his conception until his natural death; it must make people understand that the value of man – the sacredness of his life – is greater than all the goods of earthly existence.

Second, the Church should inspire and involve all men of good will to do everything possible to contribute to the establishment of social justice and common good protected by the law.

Third, the Church should unceasingly remember that Jesus Christ reveals the full truth about man. In the light of the cross of Christ, the man who suffers, whether because of old age or illness, is not a burden but a real treasure for society and for the nation. As the Holy Father observed: 'The future of people is specifically here and here, in the elderly and in children. A people that does not take care of its old people and its children does not have a future because it will not have a memory and it will not have a future. The elderly and children are the future of a people! How common it is for them to be left to one side, isn't it? Children, calm them down with a sweet, with a game: 'do it, do it; go, go'. And the elderly, do not allow them to speak, do without their advice: 'they're old, poor them''.[3]

3. The Actions of the Church for Elderly People

Starting with these fundamental rules the Church offers sick and elderly people concrete forms of pastoral activity.[4]

To take as an example the Church in Poland, first of all one should refer to care for sick and elderly people inside their families. The presence, the love and the care of a family relative are for a sick person or a person weakened by age an indispensable good. A suffering person should have a privileged place in every family because it is from him or her that there descends the blessing of God for the whole of the human community, above all for his or her family relatives. Family units that take care of their sick relatives should willingly take advantage of the charitable service organised by Catholic parishes and the various forms of help provided by non-governmental organisations, associations, institutes of consecrated life and volunteer groups.

A special field of the healing activity of the Church for sick people is *hospitals*. This pastoral care is the task above all else of chaplains but also of every kind of assistance that is of help in addressing the difficult experience of illness and of suffering. Even the work of the medical staff, if motivated by Christian love for neighbour, can be seen as the expression of a charitable apostolate. One should also note the increasingly impelling need for an integration of the service of hospital chaplains with teams made up of lay people and consecrated women – trained in an appropriate way – who could take the place of the chaplains themselves.

Sick people who are at the terminal stages of an illness need to have *palliative care and targeted pastoral care in hospices*.[5]

At the moment of death, which is decisive for the eternal destiny of man, there cannot fail to be the love of the person's family, of the medical staff and of the religious assistant.[6] The point of departure for pastoral care in hospitals is the sacramental ministry: the Holy Mass celebrated every day, the sacrament of penitence and the sacrament of the sick. Some forms specific to this kind of pastoral care are pastoral conversation and spiritual direction. On the other hand, the communal dimension is achieved through formation meetings, retreat days, prayer, spiritual exercises, pilgrimages to sanctuaries, and meetings of a social character. Given the innumerable layers of pastoral care in hospices, the people involved in this kind of service must be suitably trained and have a good grounding. Within the Forum of the Hospice Movement in Poland, courses, analysis seminars, workshops for chaplains who exercise their ministries in hospices, and postgraduate seminars on individual counselling are all organised.[7]

In order to improve the quality of health care for sick people and their families in health-care and social assistance institutions, on 10 October, as a result of an initiative of the Fatebenefratelli, the School for Pastoral Care of St. John of God at the Hospital of the Hospital Brothers was inaugurated. The aim of the school is to train priests, sisters and lay people in carrying out specialised service in the field of pastoral care in health. This school trains its students to perform the function of being a chaplain or lay assistant in pastoral care in a hospital, a hospice or another health-care institution, or in the field of home assistance or in an institution responsible for social assistance. Archbishop Zygmunt Zimowski observed: 'A Christian community that wants to act well in its service for the sick must strive to be able to train well a congruous group of presbyters and deacons, consecrated and lay men and women, as full time pastoral assistants and as extraordinary ministers of the Eucharist and volunteers. In this context it is a source of joy that the Church in Poland perceives today the urgent need for a new, multidimensional and collegial pastoral service in the health-care and social field. I am convinced that the School for Pastoral Care of St. John of God in Krakow will meet this need and match up to the hopes placed in it. This is what I hope with all my heart and I bless all of those have organised this school and will here transmit the necessary learning.

As regards the students I hope that the training obtained here will help them to serve the sick and the suffering in a radical way and that Christ who is present in our brothers and sisters will not suffer indigence'.[8]

There are very many and different forms of pastoral care for sick and elderly people engaged in at the *level of parishes*.[9] The commonest form, engaged in at the home of a sick person, is the sacramental service performed on the first Friday of every month. This service involves a visit of a priest to the home of the sick person, confession and Holy Communion. Where possible, the priests celebrate Holy Mass in the home of the sick person. An important form of support given to a sick person, and often to his or her family, is visits paid by members of parish Caritas groups, or volunteers, members of prayer and apostolate groups that are in the parish.

Liturgical services celebrated in the parish church are an important element in addressing illness and the suffering that derives from it in a Christian spirit and with a community approach. Very many parishes organise celebrations specifically for sick people, above all on the occasion of spiritual exercises in the parish, during the feast of their patron saint or at the time of the World Day of the Sick. Every so often these celebrations are organised regularly every month on the same day and can take the form of prayers to Our Lady of Fatima or a special function where prayers are said for the sick which are animated by people who are involved in the Renewal in the Holy Spirit movement.

The preaching of the Word of God and the liturgy need to be completed by a fraternal banquet (the Polish word for this is '*agapa*'). This ancient tradition is today still in use, above all in the context of the Eucharist when celebrated in small communities of faith. This reality can also be offered on the occasion of religious services specifically for the sick and for elderly people. An artistic programme and a modest meal can thus complete in an excellent way this communal celebration.

The activities of clubs for elderly people ('seniors' clubs'), for veterans or for retired people ('emeritus clubs') are another form of pastoral ministry of the Church for elderly and sick people. These institutions organise charitable balls, meetings of a recreational/social kind, pilgrimages, excursions and tourist trips. The clubs for elderly people can from time to time be offered catechesis, conferences, meetings and events of a cultural character.

4. The Activities of Caritas

As regards care for the sick and the elderly the organisation Caritas engages in activity on a grand scale. In Poland the most advanced programme implemented by Caritas is the project for environmental nursing known as 'Caritas stations of care'.[10] These stations offer nursing care and simple rehabilitation exercises. The staff of a station does not only help the family and make home care for a chronically ill person less arduous: at the same time in engages in education as regards care for the sick, rehabilitation, hygiene and diet. Independently of this programme, Caritas in the individual dioceses also manages health-care institutions – which offer rehabilitation and a health-care service for the sick[11] – as well as day houses solely for elderly people. These institutions allow elderly people and people on their own to meet each other in a circle of people of the same age; they also offer entertainment, conversation and every so often a cultural or religious programme. Some offer meals to elderly people as well as medical consultation. The day homes assure dignified conditions of life to elderly people or people with physical or mental disabilities.[12]

5. Activities Engaged in by Communities of Consecrated Life and the Association of the Apostolate of the Sick

Sick and elderly people can rely upon the charitable help of the communities of consecrated life. Religious work both in government medical institutions and in those communities which work directly in their own hospitals, health-care bodies, consultancy points and pharmacies.[13] In addition, male and female institutes of consecrated life also run old people's homes.[14]

Help given to sick people, above all at a mental and spiritual level, is the purpose of the Association of the Apostolate of the Sick which was created in 1929. This association accompanies sick people in their suffering, helps them to accept it and teaches them how their suffering can be transformed into an instrument of apostolate. A valuable support for people afflicted by chronic illnesses is the monthly review *Apostolate of the Sick* which is sent free to the homes of sick people by mail. The Association of the Apostolate of the Sick also organises national spiritual exercises, retreat days and pilgrimages to sanctuaries.

6. The Involvement of Sick people and Elderly People in the Apostolate

Elderly and sick people are not only the recipients of various pastoral activities engaged in by the Church. As the Blessed John Paul II observed: 'old age is a time of grace which invites us to unite ourselves with a more intense love to the salvifuic mystery of Christ and to participate more deeply in his project of salvation'.[15] This task opens up for elderly people 'a new opportunity in the apostolate. Involved in the task is their determination to overcome the temptation of taking refuge in a nostalgia in a never-to-return past'.[16] This task is carried out above all in the family and embraces the dimensions of culture, of education, of social activity and of the ministry of suffering and the apostolate of prayer.

The Church always needs and relies upon assiduous prayer by the sick and by elderly people. A special role in involving sick people and the disabled in the work of the preaching of the gospel message of salvation is performed by the community of the Silent Workers of the Cross. They engage in various activities, amongst which the organisation of courses of formation, retreat days and spiritual exercises. They have their own publishing activities, they organise pilgrimages and congresses and they take care of sick people and the disabled in centres managed by their community. One house of the community of the Silent Workers of the Cross, the Healing of the Sick House, is located in Glogow in Poland. The founder of the Silent Workers of the Cross, the Blessed Luigi Novarese, who on 11 May 2013 was placed amongst the ranks of the Blesseds, was greatly concerned about appreciating sick people, disabled people, and their suffering. The Blessed Luigi Novarese was convinced that suffering offered up by a sick person was 'a participation in the paschal mystery of Christ which makes [the sick person] an apostle and thus a primary example and prophecy for the valuing of every form of suffering that is present in the life of man'.[17]

In order to engage in the above mentioned forms of apostolate in an effective way, sick people and the elderly need suitable formation that must take into account the decline in their physical strength and every so often also their weaker physical and mental potentialities.[18]

Conclusion

These forms of pastoral and apostolate activities do not constitute a complete and exhaustive picture of the many sided Christian mission for the benefit of sick people and the elderly. The involvement of our communities in this field of pastoral care requires an unceasing effort and the search for new methods in order to reach people who are living a malaise that is caused by illness or old age. We need a mobilisation of pastoral activities directed towards activating a 'specific' apostolate for suffering people. Only in this way will we be able to oppose the contemporary dominant 'culture of waste' with another culture, one based on the Gospel – the culture of acceptance and charity.

Notes

[1] II Polski Synod Plenarny 1991-1999, 'Posługa charytatywna Kościoła', p. 24.

[2] Pope Francis, 'General Audience' 5 June 2013, *L'Osservatore Romano* (Polish edition), 34 (2013) 8-9, pp. 48-49.

[3] Pope Francis, talk at the Holy Mass of 30 September 2013: http://papiez.wiara.pl/doc/1724334.Papiez-Nie-swietna-organizacja-a-radosc-i-pokoj (accessed 10.10.2013).

[4] Cfr. C. Krakowiak, 'Eklezjalny charakter troski o chorych', in E. Szczotok - A. Liskowacka (eds.), *Program duszpasterski na rok 1995/96*, Katowice, 1995, 210-224; B. Drożdż, 'Duszpasterstwo chorych', in R. Kamiński – B. Drożdż (eds.), *Duszpasterstwo specjalne*, Lublin, 1998, 273-290; M. Kalinowski, 'uszpasterstwo chorych', *Roczniki Teologiczne* 45 (1998) 6, 179-190; R. Szczygieł, *By odgadnąć krzyż. Vademecum Chorych,* Poznań, 1991; Z. K. Szostkiewicz, *Vademecum duszpasterza chorych* , Warsaw, 1993.

[5] Cf. M. Kalinowski, *Duszpasterstwo hospicyjne. Studium pastoralne na podstawie badań wybranych ośrodków hospicyjnych w Polsce*, Lublin, 2000; A. Bartoszek, *Człowiek w obliczu cierpienia i umierania. Moralne aspekty opieki paliatywnej*, Katowice, 2000.

[6] John Paul II, 'Wobec tajemnicy śmierci', meeting with those taking part at the conference on care for dying people, organised by the Bioethical Centre of the Catholic University of the Sacred Heart, 17 March 1992, in *Ewangelia cierpienia. Wybór homilii, przemówień i dokumentów*, Krakow, 1997, p. 181.

[7] Cf. M. Kalinowski, *Duszpasterstwo hospicyjne. Studium pastoralne na podstawie badań wybranych ośrodków hospicyjnych w Polsce*, Lublin, 2000; A. Bartoszek, *Człowiek w obliczu cierpienia i umierania. Moralne aspekty opieki paliatywnej*, Katowice, 2000.

[8] Z. Zimowski, 'Kościół zawsze wierny w służbie miłości wobec chorych i cierpiących', in A. Muszala, J. Binnebesel, P. Krakowiak, M. K*robicki (eds.), Dolentium Hominum. Duchowni i świeccy wobec ludzkiego cierpienia*, Krakow, 2011, p. 27.

[9] Cf. W. Przygoda, *Apostolski wymiar wolontariatu charytatywnego w Polsce. Studium teologicznopastoralne na podstawie badań wolontariuszy z parafialnych zespołów Caritas*, Lublin, 2012.

[10] This project was inaugurated in 1992 in Dobrzeń Wielki in the diocese of Opole. The dynamic development of the network of the Caritas stations of care began, however, only after the agreement was signed between Caritas of Poland and Caritas of Germany, which in 1994-1997 supported this project with funds: cf. R. Chormiński, '*Profesjonalizm i troska. Stacje Opieki Caritas w Polsce*', *Biuletyn Informacyjny KAI* (05.08.1997) n.31, pp. 9.

[11] In the year 2001 at the Caritas care stations 70 rehabilitation surgeries were in operation, of which there were 37 in the local area of the diocese of Opole, and 12 in the diocese of Gliwice. The caritas diocesan organisations also ran 11 medical surgeries which provided a basic medical service. The Caritas organisation of the diocese of Kielce was responsible for six such surgeries: cf. *Informator Caritas 2002/2003*, pp. 27-28; *Fenomen Caritas*, *Biuletyn Informacyjny KAI* (27.05.1999) n. 21, p. 31.

[12] In the year 2001 the diocesan Caritas organisations ran 10 day homes and 18 full stay homes for elderly people and people on their own: cf. *Informator Caritas 2002/2003*, 32-33.

[13] In the year 2001 the male and fenakle institutes of consecrated life ran 5 hospitals, 6 non-governmental medical institutions, 7 herbal pharmacies, 32 nursing homes with more than 25,000 beds for people with mental disabilities and illnesses of the nervous system, 40 health-care institutions with more than 33,000 beds for people with chronic illnesses: cf. B. Łoziński, *Leksykon zakonów w Polsce. Instytuty życia konsekrowanego i stowarzyszenia życia apostolskiego*, Warsaw, 2002, pp. 455-460.

[14] The data are for the year 2001: cf. Łoziński, *Leksykon zakonów w Polsce*, pp. 456-459.

[15] John Paul II, *Dar długiego życia*, homily during the Great Jubilee of Elderly People, 17 September 2000, *L'Osservatore Romano* (Polish edition) 21 (2000) 11-12, p. 14.

[16] John Paul II, *Christifideles laici*, n. 48.

[17] The statutes of the Centre of Volunteers of Suffering, http://www.sodcvs.org/sito/it/documenti/statuti-sodc-e-cvs.html (accessed: 10.10.2013).

[18] Cf. J. Ostrowski – W. Przygoda, 'Seniorów duszpasterstwo', in R. Kamiński – W. Przygoda – M. Fiałkowski (eds.), *Leksykon teologii pastoralnej*, Lublin, 2006, pp. 789-793; cf. M. Marczewski, 'Z upływem lat oswajamy się z myślą o „zmierzchu" (Duszpasterstwo ludzi starszych)', *Roczniki Naukowe Caritas* 10 (2006), pp. 23-36.

6. The Contribution of the Catholic Church in the Democratic Republic of the Congo at the Service of Sick Elderly people

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This paper is organised around three points. First of all, I will seek to describe briefly the context, explaining what the Church-family of God in the Democratic Republic of the Congo does for sick elderly people. I will then identify what the permanent challenges of this activity are today. And then I will end the paper by dwelling on the meaning and the value of the activity of the Church in this field.

1. The Context

In the Democratic Republic of the Congo average life expectancy is not as high as in Europe or in America. Life expectancy, indeed, is estimated as being fifty years. At the basis of this phenomenon there are various factors. The most important ones seem to be, in my view, the difficult conditions of life of a post-civil war country, the precariousness of health care, a lack of means of subsistence and the malfunctioning of the health-care services at a national level. This means that medical care does not reach all the citizens of the country. It is thus easy to understand why those diseases that are curable in other lands continue to kill very many children and young people, as well as elderly people, in the Democratic Republic of the Congo, as indeed also occurs in many other African countries. For that matter, it is not even easy to speak about elderly people in the Democratic Republic of the Congo. Indeed, one should pose the following question: at what age do people become elderly in the Democratic Republic of the Congo when the conditions described above and all the signs of old age are visible in those who are only fifty?

In general, elderly people in Africa, and especially in the Democratic Republic of the Congo, have always benefited from the esteem of the members of their family and of society. In good African traditions, these people constitute a valuable treasure for the members of the family and of the village. In African culture, elderly people are esteemed as a source of wisdom and of culture. Whatever their state of health, they often live with their families in the broad sense of the term. Care for them, in principle, is the responsibility of their family relatives whatever the nature of the kinship tie. Elderly people are appreciated as the educators of the cultural and social values of the community, the guardians and mediators of traditions that they hand down to children and grandchildren. Some of these elderly people are the victims of belief in witchcraft.

What I have just observed concerns life in villages. Things are different in the cities and the urban conglomerations. In these places family ties are not as strong as they are in the villages. This reflects the fact that elderly people who live in these non-traditional contexts are for the most part pensioners who have worked all their lives and whose income has only been their wages. Unfortunately, as is the case in most African countries, many of these pensioners do not receive a pension that allows them to have a decent lifestyle. As a consequence, they become a burden for their family relatives, if they have any, despite the low wages of recent years. As they do not have adequate welfare coverage, their state of health is a social problem and a challenge for the pastoral care of the Church-family of God in the Democratic Republic of the Congo.

At the present time the problem of treatment and care for elderly people is raised with a certain intensity inasmuch as living conditions are constantly deteriorating. Over 70% of the population lives in a state of extreme poverty and this is something that makes old age even more vulnerable. Poor families abandon their weakened members because of a lack of money. In the large cities, at times, if not often, we witness total abandonment, that is to say a rejection of these elderly people who are arbitrarily treated, in particular by witchdoctors, malefactors and diabolical individuals.

In the Democratic Republic of the Congo, at the governmental level it is the Ministry of Social Affairs that has responsibility for treatment and care for elderly people. A national policy exists in this area but its implementation leaves a great deal to be desired. Most of the time, non-profit making organisations work in this field with the help of government funding.

2. The Services of the Catholic Church in the Democratic Republic of the Congo for Sick Elderly People

2.1 Organisation at a national level

In the Democratic Republic of the Congo the Catholic Church is present throughout the country thanks to its forty-seven dioceses which cover a population of about seventy million inhabitants. Pastoral cooperation between the bishops takes place within the framework of the National Bishops' Conference of the Congo. One of the episcopal commissions that is a part of this conference is the Episcopal Commission 'Caritas-Development' whose mandate is to promote development, health and solidarity. This commission works through Caritas-Congo which, according to the law of the Congo, is a non-profit making organisation, and is its technical office in this field.

According to the statutes of the National Bishops' Conference of the Congo, Caritas-Congo has the mission of 'increasing, through reflection and action, the efficacy of the contribution of the Church to the efforts to achieve the integral promotion of the person and the human community in conformity with the social doctrine of the Church, the fundamental option of the Church and the pastoral directives of the National Bishops' Conference of the Congo in order to lead the Christian community and each one of its members to the promotion of justice and peace, charity and solidarity'.

In the field of health, the Church-family of God in the Democratic Republic of the Congo signed a framework agreement with the government of the Congo through its Ministry of Health starting in the year 2007. This agreement allows the Catholic Church, respecting its own ethical principles and its view of human beings, to engage in health-care activity or to manage its own or public medical institutions, in conformity with national policy. At a diocesan level, this service is ensured by the Diocesan Office of Medical Works. At a national level, the coordination of this health service within Caritas-Congo ASBL is a part of the service for the promotion of health. In order to ensure greater efficacy in its activities, Caritas-Congo ASBL is organised as a network both at a national, diocesan and parish level and at the level of the Basic Living Church Communities (CEVB).

As regards the supply of health-care services, the Catholic network manages over 50% of the confessional health-care infrastructures of the country. It has 237 hospitals, 167 health-care centres of primary importance, and 1,057 health-care centres, that is to say a total of 1,455 health-care entities. In addition, the Caritas network in the country manages 92 nutritional centres, 4 psychiatric centres, and 18 centres for people who live with a handicap.

2.2 Actions at a Diocesan level in the Democratic Republic of the Congo for Sick Elderly People

Care for sick elderly people is a constant concern of the Church in the Democratic Republic of the Congo. This is an integral dimension of its pastoral activity which goes back to the period of the pioneers of evangelisation. The missionary evangelising action promoted by the pioneers who worked hard to create these diocesan churches also included the dimension of providing care to people. For this reason we find in most of the parishes (Catholic missions) places organised to admit elderly people, institutions that are termed 'homes for the elderly'

In these places health care is provided and overall care is ensured and takes the form of nutritional support, clothes, psycho-social counselling and spiritual accompanying. The psycho-social aspect has a capital importance in the African context inasmuch, in general, there is the tendency to equate the various forms of senile dementia with the effects of witchcraft or diabolic possession. People who receive this overall care are for the most part widows and people with handicaps who have lost all their relatives or have been abandoned by their families for a variety of reasons.

In various dioceses of the Democratic Republic of the Congo this work is carried out tirelessly by certain Institutes of Consecrated Life according to their respective charisms. Today some Congregations, above all ones of women of diocesan or pontifical right, ensure care and welcome for sick elderly people in hospices specifically created for this purpose. The illnesses and the suffering of these people are attended to by women religious or such people are looked after by certain health-care institutions that are managed by the Church. As I observed above, this service is provided at no cost because these elderly people are generally poor, have no income and do not receive a pension. The women religious involved in this apostolic field and some volunteers provide them with care according to their resources and they do this in the belief that through them they encounter and serve Christ. As St. Matthew narrates: 'whenever you did it to one of the least of my brethren you did it to me' (cf. Mt 25:40).

In general, organised treatment and care for sick elderly people is not known about or developed in the traditions and customs of Africans. This is an imported Western practice because in Africa vulnerable people are totally the direct responsibility of their families and this is also the case in the Democratic Republic of the Congo.

The identifying of poor elderly people is the work of Caritas at a parish level through the Basic Living Church Communities (CEVB), whereas daily treatment and care in the hospices is provided by volunteers or women religious. In addition, at the level of the parish work of Caritas or the CEVB collections are organised for them in products or money.

As regards medical treatment and care, people who are seen as being poor are directed to the health-care structures of the Church for free elementary care. Grave cases generally require the payment of a fee and those who administer the hospices are often powerless, although people of good often provide help.

The spiritual accompanying of sick elderly people is a part of the ordinary tasks of priests who work at the level of parishes or of chaplains appointed for this purpose in certain hospices and hospitals who admit a significant number of sick elderly people. As can be observed, the challenges relating to treatment and care for these people are enormous.

3. Four Challenges that Should be Addressed

I here list the following important challenges relating to the question of the contribution of the Catholic Church in the Democratic Republic of the Congo as regards its service to sick elderly people:

Overall treatment and care provided by the Church that unites the medical, psycho-social, moral and spiritual aspects of sick elderly people within a context of limited resources (poverty).

The suitable training of competent personnel who are able to conjoin technical skills and expertise with ethical and spiritual values within the multidimensional that is provided to sick elderly people.

National care coverage in infrastructures that admit elderly and/or sick people.

Activity involving advocacy with people in government with a view to achieving treatment and care for sick elderly people that is of a decent level through the public authorities and the activity of Church associations involved in providing a service to this category of people.

Conclusion

As you will have noticed, in the Democratic Republic of the Congo sick elderly people constitute a category of poor people for the Catholic Church. There are in fact people who are poor at the level of health, poor at the level of economic resources in facing up to this vital question, poor at the level of a health care that is suited to their suffering, and poor at the level of how much attention that is paid to them in the policies of our governments. What is done in Church institutions or what is done by the Church to help them is a drop in the ocean of their misery and their desire to live in a better way and to somewhat reduce their suffering. But we believe that this activity of the Church constitutes a sign and a message as regards the value and the meaning of their lives which goes beyond any utilitarian and efficiency-based logic. The action of the Church to help them is a prophetic deed which reminds us of the value and the dignity of the life of each person to whose service the Church-family of God is committed. ■

Recommendations at the End of the Twenty-eighth International Conference

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The papers have been very diversified and have addressed all aspects of sick and dependent elderly people. They have amply addressed the subject of Alzheimer's disease which dominates the question of chronic diseases because of its prevalence in the elderly part of the population, with percentage levels continuing to grow throughout the world. Although the papers have highlighted a disparity of care as regards countries and their socio-economic levels, at times within communities where one could have expected a certain homogeneity, such as in the case in Europe, it is evident that the problems connected with treatment and care are broadly shared.

Amongst the recommendations that we can make at the end of this meeting, I believe that one should emphasise the principal message concerning care and treatment for the sick which cannot be summarised in technical treatment or in the prescribing of examinations or medical products. Although the patient has deteriorated a great deal at the level of his or her intellectual or physical functions, he or she remains an individual who requires a special understanding which takes account of his or her personal history in all its dimensions: the familial, the social, the cultural, the moral and the religious.

Another important message to emerge has been the need for *prevention*, in particular in the case of Parkinson's disease, starting with elementary school, because education levels play an important preventive role in this field. Together with physical exercise and the prevention of depression, in the long term one could reduce the number of patients by 30%. In these areas, the intervention of public authorities and of political decisions is essential and requires specific action plans that must be assessed.

The need for *information* also appears to be crucial, in particular for family relatives and social assistants who are often confused when faced with people who have Alzheimer's disease and do not know how to react or how to help the family relative who has been afflicted. New initiatives should be attempted in order to avoid or delay the placing of patients in institutions. The family cannot always cope but inter-generational community experiences have been proposed which have had very encouraging results: they involve individuals of all ages in greater *solidarity*, thereby avoiding the exclusion of sick elderly people who need strong social interactions. This forms a part of their treatment and at times produces better results than the use of medical products. However, one should avoid establishing unreasonable goals which both the patient and those who surround him or her may not be able to attain. The malady is irreversible and has to be accepted, even though this can be painful.

The final message is a message of hope: we age over a longer period of time, we live more, but we also remain young longer. The ageing of the population should never be experienced as a drama by those in government: it should be seen as an opportunity! ▪

Conclusions and Recommendations

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This twenty-eighth international conference of the Pontifical Council for Health Care Workers on the subject 'The Church at the Service of Sick Elderly People: Care for People with Neurodegenerative Pathologies' has approached the subject and its questions and issues dealing with a plurality of aspects: from the most typically clinical to those that are pastoral in character, also addressing the psychological, spiritual, familial, social, economic and political aspects. In these 'Final Recommendations' – which have to be condensed into a few lines – I leave to one side the medical aspects, for that matter of a rather problematic character given the lack of knowledge about their medical emergence (above all as regards Alzheimer's disease), and therapies that are strictly medical in character. I would like to approach the core and central points on three fronts: the socio-cultural front, the ethical-values front and the ecclesial-pastoral front.

1. The Socio-Cultural Front

The following emerged as the factors that determine and worsen the fate of sick elderly people:

– *The ageing of the population*, caused by an increase in life expectancy.

– The reduction of the role of social support assured by the *family* which because of the gradual weakening of the family network no longer has the characteristics and the solidity that it once had.

– The frequent *marginalisation of elderly people*.

– *The utilitarian and consumerist mentality*: *market oriented*.

– The international *economic crisis* which has caused:

- A steady reduction in national funds for social policies.
- A calling into question of that idea of solidarity that seemed to be a bulwark shared by all constitutional democracies.
- Social poverty which has generated health-care poverty.

With the ageing of the population, the number of these sick people is destined to steadily increase, with grave socio-economic repercussions. In parallel, social costs will also increase.

– *Changes in the family*: a decrease in the size of families, divorce, cohabitation rather than marriage, the fragmentation of the family, with adult children who live far away from their parents.

– The consumption of *alcohol*, smoking, a *sedentary life* and *obesity* are forms of behaviour that work together to increase chronic degenerative diseases.

– The *backward situation in Africa* leads to an earlier presence of diseases and maladies which in developed countries occur during old age. Thus Msgr. Djomo asks: 'at what age does a person become old when all the signs of ageing are visible in those who are only fifty?'

2. The Ethical-Values Front

The known characteristics are the following:

– *The denunciation*

- of euthanasia and medically assisted suicide as an inhuman and unacceptable outcome for the problem;
- of the utilitarian conception of life which deprives the lives of elderly people of value, especially if they are effected by neurodegenerative and disabling diseases, thereby opening up and fostering the pathway towards euthanasia;
- of the 'throwaway culture' as it is called by Pope Francis: 'men and women are sacrificed to the idols of profit and consumption: this is the 'throwaway culture''.

– *Care for the person in his or her totality* which leads illness and treatment to be seen in terms that are not strictly physical and medical but integral. This is the holistic vision of sick people and of care and treatment. We have to leave a medical-centric and medical product-centric vision of dementias. We should move to a vision and treatment that are at one and the same time relational, emotional and spiritual. 'To see a person only through the lens of illness is to run the risk of losing our sense of him or her as a person. To describe dementia as a steady and irreversible loss of the cerebral functions is to run the risk of seeing a diminution of the person…One can see dementia as leading to the loss of cognitive functions without seeing it as a consequent loss of the person' (McInerney).

– *The polarisation of care* – in the absence of medical therapies – *around rehabilitation*, with the aim of strengthening the patient or at least delaying cognitive and functional decline, reducing psychological and behavioural disturbances and thus improving the quality of life of sick people and their families. Even though, because of the degenerative and progressive nature of the illness, rehabilitation cannot aim at a '*restitutio ad integrum*', it can help a sick person to conserve the best conditions possible for the longest period of time possible. Rehabilitation concerns the *person* (seeking cognitive, functional, psychological and behavioural compensation). At the same time it concerns *the environment* (seeking to construct a new adaptive and prosthesis balance) and the family (to which is offered advice on psychological and educational support, skills and expertise as regards the illness, the resources of the local area, legal questions, etc.).

– *Solidarity* which activates and brings together people who are different by culture, religion and background but who share the idea that there should be a mutual recognition between human beings and support so as to ensure that the weakest people do not suffer want.

– *Subsidiarity* which leads to privileging and giving more to those who are in need.

– Support for families burdened by the presence of, and care for, an elderly person with degenerative pathologies: support that takes the form of support services and strategies by activating a network of social relationships, especially with volunteer associations; helping to address feelings and emotions, to manage stress, and to prevent and overcome feelings of guilt.

– *Integration and social cohesion*, which have a preventive and therapeutic efficacy in relation to loneliness, which dementia tends to provoke in elderly people.

– *Prevention*, both of a distance kind, through correct lifestyles (from alimentation to movement), and near to hand: 'Prevention must be at the heart of support and taking responsibility for elderly people' (Lareng).

– *Palliative care*, whose value and validity should be recognised and whose use should be extended.

– *Dying with human and Christian dignity,* which is a real right of incurable elderly people, with all deformations in the form of euthanasia rectified and purified.

– *In the specifically ethical-political field:*

• The peculiarity and complexity of this phenomenon requires an extraordinary and intelligent capacity for governance.

• *Welfare is involved*, and its reform, in order to respond in an appropriate and fair way to two phenomena in particular: the economic crisis and the ageing of the population, with the degenerative diseases that ageing involves.

3. The Ecclesial-pastoral Front

Psalm 92:15, 'still bear fruit in old age and are always green and strong', has been the leitmotiv and central theme.

The recommendations that have emerged are the following:

– *To accompany elderly people humanly and spiritually during their illnesses.* 'Higher levels of spirituality have been associated with a slower advance of Alzheimer's disease. The existential wellbeing and the spirituality of patients with amyotrophic lateral sclerosis (SLA) is connected with the psychological wellbeing of their caregivers' (Bussing). These data call upon the spirituality – the spiritual quality of life – of caregivers: health-care and pastoral workers, volunteers, family relatives and friends.

– The icon *par excellence* for all caregivers involved in various ways in the provision of care is the Good Samaritan.

– To promote in every parish a 'centre for elderly people' which is experienced as a *centre of charity*, animated by the faith of believers in Christ and open to welcome and care for the sick and the cooperation of workers who belong to other religions.

– Msgr. Andrea Pio Cristiani, in particular, evoked a theology of prevention which should explore and promote the safeguarding of the body, starting with the warning of St. Paul: 'Do you not know that your body is a temple of the Holy Spirit?'. The *Catechism of the Catholic Church* summarises the relationship of prevention and morality when it states that: 'Life and physical health are precious gifts entrusted to us by God. We must take reasonable care of them' (Art. 2288).

– *Pastoral Care should also acquire the holistic principle* in care for the elderly, directed towards caring for both the soul and the body. The strength of the sacraments meets such Christian holism in particular.

– The Christian difference is seen in the *style* and the *passion of charity*. 'In Australia', observed, Bishop Donald Sproxton, 'we feel fortunate to be cared for by a Catholic service: a service based on the parable of the Good Samaritan where patients know that they are in safe hands but also in compassionate hands'.

– An appeal was made to *ecclesial and privileged charitable care for the elderly*. Following the approach outlined by Benedict XVI: 'The quality of a society or of a civilisation can be judged by the way in which it treats elderly people'. And of Francis, who united care for the elderly with care for children, who observed: 'the future of a people lies precisely here, in the elderly and children. A people that does not take care of its old people and its children does not have a future because it will not have a memory and it will not have promise! The elderly and children are the future of a people'.

Conclusion

The conclusion is in the key of *hope*. This was well represented by Prof. Louis Lareng: 'We are always full of confidence as regards our goals because hope is the anchor of our lives. Who is the fool who dares, without hope, to embark on this sea of the new century, the home of winds and storms'? And Christian hope does not disappoint, we are assured by St. Paul, for the love of God has been poured into our hearts by means of the Holy Spirit, who is God's gift to us (Rom 5:5). 'Because we have this hope, we are very bold' (2 Cor 3:12).

And with this appeal to the boldness of hope, this twenty-eighth international conference of the Pontifical Council for Health Care Workers comes to an end. ■

XXIX International Conference
of the Pontifical Council for Health Care Workers

‘The Person with Autism Spectrum Disorders: Animating Hope’

Vatican City, 20-22 November 2014

Thursday 20 November

Morning Session

7.30 **Celebration of Holy Mass in St. Peter’s Basilica at the Altar of the Chair**
His Eminence Cardinal George Pell
Prefect of the Secretariat for the Economy (Holy See)

9.00 **Opening Address**
The Solicitude of Pope Francis for the Sick and the Suffering
H.E. Msgr. Zygmunt Zimowski
President of the Pontifical Council for Health Care Workers (Holy See)

Chairman:
Dr. Mary Healey Sedutto
Founder and Executive Director Hope for a Healthier Humanity Foundation (USA)

9.30 **Greetings of Authorities**

10.00 **Prolusion**
Autism Spectrum Disorders in Childhood: a ‘Challenge’ for Pastoral Care of the Family
Prof. Stefano Vicari
Head of Child Neuropsychiatry Unit, Bambino Gesù Children’s Hospital, Rome (Italy)

10.30 **The Anthropology of the Perception of Pain in Autism Spectrum Disorders**
Prof. Christian Flavigny
Director of the Department for Children and Adolescents, CHU Hôpital Pitié Salpêtrière, Paris, (France)

11.00 Break

Autism spectrum disorders: epidemiology and health-care policies

Chairman:
Dr. Roberto Bertollini
Scientific Director and Representative of the WHO (World Health Organization) at the European Union (Belgium)

11.30 **The Historical and Epistemological Background to Autism Spectrum Disorders**
Prof. Francesca Happé
Professor in Cognitive Neurosciences at the University of London (United Kingdom)

11.50 **Global and Coordinated Efforts to Manage Autism Spectrum Disorders**
Dr. Shekhar Saxena
Director of the Department of Mental Health and Substance Abuse, WHO (Geneva)

12.10 **Autism Spectrum Disorders: European Policies and Strategies**
Prof. Fabrizio Oleari
Past President of the Higher Institute for Health Care (Italy)

12.30 End of Session

Afternoon Session

15.00 **Health Policy Strategies Adopted by the World Health Organization in Favour of People with Autism Spectrum Disorders (ASD)**

Chairman:
Prof. Romano Marabelli
General Secretary of the Ministry of Health (Italy)

BANGLADESH
Dr. Saima Hossain
Chair-National Advisory Commitee on Autism

MALAYSIA
YB Datuk Seri Dr. S. Subramaniam
Minister of Health

ITALY
Prof. Romano Marabelli

16.00 **Discussion**

17.00 Break

Research, prevention and therapies

Chairman:
Prof. Kang-E Michael Hong
Professor Emeritus at the National University of Seoul, Faculty of Medicine, Department of Child and Adolescent Psychiatry (Korea)

17.30 **Advances in Genetic Research**
Prof. Daniel H. Geschwind
Director of the Neurogenetics Programme at the Centre for Research and Treatment of the University of California, Los Angeles (USA)

17.50 **The Role of Environmental Exposures in the Aetiology of Autism: a Retrospective View of the Last Decade – New Results and New Frontiers for the Future**
Prof. Irva Hertz-Picciotto
Professor and Director of the Environmental and Work Health Division UC Davis M.I.N.D. Institute (USA)

18.10 **The Brain and Behaviour**
Prof. Filippo Drago
Full Professor of Pharmacology at the University of Catania (Italy)

18.30 **The Role of Early Medical and Rehabilitation Therapies in the Area of Prevention**
Prof. Marina Gandione
Professor of Child Neuropsychiatry at the University of Turin (Italy)

18.50 End of Session

Friday 21 November

The early diagnosis and the identification of autism spectrum disorders

Morning Session

Chairman:
Dr. Maurizio Brighenti
Director of the Centre for Autism Diagnosis, Treatment and Research, Verona (Italy)

9.00 **The BASIS Network – a British Study on the Autism of Children amongst their Siblings**
Prof. Mark Johnson
Director of the Centre on the Brain and Cognitive Development, Birkbeck College, University of London (United Kingdom)

9.20 **Non-invasive Instruments for the Early Diagnosis of Autism Spectrum Disorders: the NIDA Project**
Prof. Maria Luisa Scattoni
Coordinator of the Project for the Early Recognition of Autism of the Higher Institute of Health Care (Italy)

9.40 **Predictive Behavioural Markers of ASD in Neonates at High risk**
Prof. Lonnie Zwaigenbaum
Professor at the Department of Paediatrics and Director of the Centre of Research on Autism at the University of Alberta, Edmonton, AB (Canada)

10.00 Break

Pharmacological, behavioural and innovative treatment

Chairman:
Prof. Salvatore Cuzzocrea
Full Professor of Pharmacology at the University of Messina (Italy)

10.30 **Evidence-based pharmacological and rehabilitative therapies: current status and prospects**
Prof. Antonio M. Persico
Professor of Neuropsychiatry at the Bio-medical Campus University of Rome (Italy)

10.50 **Complementary and Supporting Medicine: an Overall Vision**
Dr. Catherine Doyen
Psychiatrist at the Sainte-Anne Hospital Centre of Paris (France)

11.10 **The Treatment of Children with Autism Spectrum Disorders in Low- and Middle-Income Countries: the Role of Non-Specialist Treatment Providers**
Dr. Mashudat A. Bello-Mojeed
Psychiatrist at the Centre for Children and Adolescents at the Federal Neuropsychiatric Hospital of Lagos (Nigeria)

11.30 **The Ethical and Legislative Aspects of Research and Treatment**
Prof. Roberto Dell'Oro
Director of the Institute of Bioethics at the Loyola Marymount University (USA)

11.50 **The Contribution of Art, Religion and Communication in the 'Treatment' of People with Autism Spectrum Disorders**
Dr. Marina Norsi
Former Director of the Rehabilitation Center for Child Neuropsychiatry at the Beer Sheva Hospital; Consultant for Child Neuropsychiatry (Israel)

12.10 **Discussion**
DISCUSSANT
Prof. Massimo Aliverti
Child Psychiatrist, Medical Director at the St. Anna Hospital of Como (Italy)

13.10 End of Session

Psychosocial, cultural, educational, theological and pastoral aspects

Afternoon Session

15.00 **ROUND TABLE: the Contribution of the Various Figures Involved in the Accompanying and Education of People with ASD**

Chairman:
Dr. Richard Mills
Research Director,
National Autistic Society (United Kingdom)

PARENTS
Dr. Francesca Malaffo
Systematic Family Psychotherapist at the Child Neuropsychiatry of the ULSS 20, Verona (Italy)

EDUCATORS
Prof. Carlo Hanau
Lecturer in Medical Statistics and the Planning and Organisation of Social and Health-care Services, the Department of Education and Human Sciences, University of Modena and Reggio Emilia (Italy)

PASTORS
H.E. Msgr. Nicolas Djomo
Bishop of Tshumbe, President of the National Bishops' Conference of the Democratic Republic of the Congo and former Professor of Clinical Psychology at the University of Kinshasa (DRC)

SOCIO-PSYCHO/HEALTH-CARE WORKERS
Prof. Salomé Recio
Pedagogue and Professor of Childhood Education (Spain)

VOLUNTEERS
Mr. Bob and Mrs. Suzanne Wright
Co-founders of Autism Speaks Association (USA)

16.15 **The Theological Foundations of Religious Education in People with Autism Spectrum Disorders (ASD)**
Rev. Prof. Andrzej Kiciński
Director of the Institute of Catechetical and Pastoral Theology, Catholic University of Lublin (Poland)

16.35 Break

17.00 **The Pastoral Accompanying of Families with People with ASD**
Msgr. Pierangelo Sequeri
Member of the International Theological Commission (Italy)

17.20 **Experiences from some Christian Communities**

Chairman:
Rev. Prof. Telesphore Malonga
Professor of Ecclesiology and Public Law, the Catholic University of Graben-Butembo (DRC)

AFRICA
Dr. Charles Masulani Mwale
Director of Services, St. John of God Hospitaller Service, Mzuzu (Malawi)

AMERICA
Dr. Janice Benton
Executive Director National Catholic Partnership on Disability – NCPD (USA)

EUROPE
Prof. Arndt Büssing
Professorship on Quality of Life, Spirituality and Coping; Center for Integrative Medicine; Faculty of Health,
Witten/Herdecke University (Germany)

18.20 **Discussion**

18.40 **Presentation of the Conclusions and Recommendations**

Dr. Rosa Merola
Psychologist, Psychotherapist;
Expert Consultant Prison Psychologist of the Ministry of Justice (Italy)
Consultor of the Pontifical Council for Health Care Workers

Prof. Massimo Petrini
Dean of the International Institute of the Pastoral Theology of Health Care, Camillianum (Italy)
Consultor of the Pontifical Council for Health Care Workers

Msgr. Tony Anatrella
Psychoanalyst (France)
Consultor of the Pontifical Council for Health Care Workers

19.30 End of Session

Saturday 22 November

10.00 **Meeting of Prayer and Testimonies with People with ASD, their families and Associations of the Sector in the Paul VI Audience Hall**

12.00 **General Audience with the Holy Father Francis**

During the International Conference, works of a Taiwan artist Mr. Leland Lee will be exhibited