

4.

THE PRINCIPLES WHICH ENLIGHTEN OUR HOSPITALITY

Accepting the Church's call to become increasingly more conscious of the evangelising mission of every group or centre/activity within the Church, the Order feels committed to clearly developing its identity as it plans the New Hospitality in the light of what we call the 'Culture of the Order'. All of us are committed to this hospitaller culture, Brothers and Co-workers together embodying the principles which enlighten our hospitality in all we do. We will now examine these principles one by one.

4.1 *The dignity of the human person*

4.1.1 - *Respect for the human person.*

The creation of man and woman in the image of God (Gen 1:27) gives them an undeniable dignity. Of all the living beings, the human being is the only one which resembles God, is called to communication with God, and is able to heed and respond to God. The dignity of every human being in God's eyes is the basis of their dignity in the eyes of man, and in their own. This is the ultimate reason for the fundamental equality and fraternity of all humanity regardless of ethnicity, nation, sex, origins, culture and social class. This is the reason why no human being may use another human being as if they are things or objects. On the contrary, everyone must be treated as autonomous beings responsible for themselves, and be shown respect.

Our duty of self-esteem and self-love comes from the dignity of the human being in the eyes of God. Consequently, we must all consider ourselves to have worth, and take responsibility for looking after our own health. And our duty to love our neighbour as ourselves also comes from the dignity of every human being in the eyes of God, as is the fact that human life is sacred and inviolable, essentially because in the face of every human being there is a ray of the glory of God (Gen 9:6).

4.1.2 *The universal nature of respect.*

Respect for the dignity of the human person, created in the image and likeness of God, requires everyone, without exception, to consider our neighbour as 'another self', primarily taking care of their lives and providing them with the means they require to be able to live in dignity.¹ It has to be made clear that the dignity of every human being is a fact, whatever may afflict them, whatever limitations may be imposed on them, and to whatever level of social alienation they may be reduced.

Respect for the dignity of the human person created in the image and likeness of God is present in the philosophy and increasing international awareness of the wide range of human rights.

As persons, all men and women are equal and deserve equal consideration and respect. Dignity is inherent in the human being by virtue of being the subject of rights and duties.²

4.1.3 *Welcoming the sick and the needy.*

¹ Cf. SECOND VATICAN COUNCIL. Pastoral Constitution *Gaudium et Spes* (GS), 27

² The concept of human dignity and rights of the person are intimately connected in the Universal Declaration of Human Rights (1948), The International Convention on Economic Social and Cultural Rights (1966), The International Convention on Civil and Political Rights (1966), The Convention on Human Rights Biomedicine, better known as the "Oviedo Convention" (1997). Even though these Declarations do not make it clear and explicit on what human dignity is based, they recognise all of them as being inherent to the human being and also and also recognise the equal and inalienable rights of all the members of the human family as the foundation of freedom, justice and peace in the world.

Since the value and human dignity of the sick and needy are being more frequently questioned today when suffering from pain, disabilities and death, and run the risk of being overshadowed, by taking care of the sick and needy, the Hospitaller Order declares to all humanity the wonderful legacy of faith and hope it has received from the Gospel.

Following the example of St John of God, the Hospitaller Order sees Jesus' attitude to the weakest and the socially marginalised as a call to us to be committed to defending and fostering fundamental rights based on respect for human dignity.

Considering the different ways in which the Order expresses its charism today, we feel that there are a number of areas in which there are particularly meaningful signs of the Gospel in terms of the New Hospitality:

- *the homeless*: expressing the dimension of free-giving which our society, driven by the need for efficiency and productivity, almost denies;
- *the terminally ill*, expressing the value of life at the moment of death;
- *AIDS victims*: overcoming marginalisation due to fear and irrational prejudice;
- *drug-addicts*: loving people who are unable to love themselves;
- *immigrants*: welcoming in Jesus, in the stranger, as the genuine expression of hospitality;
- *the elderly*: affirming the value of human life in every stage of existence;
- *the chronic sick and disabled*: expressing the value and dignity of the human person.

Wherever there is poverty, disease, or suffering is a special place in which we, as Brothers and Co-workers, making up the St John of God Family, practise and live the Gospel of mercy.³

4.2 Respect for human life

4.2.1 Life as a fundamental right of the person.

Life is a fundamental right of the person and a prior condition for enjoying other rights. Everyone must be acknowledged as possessing the same rights as all other men and women as far as life is concerned.

The duty to self-fulfilment incumbent on everyone – viewing our existence as a gift but also as a commitment to act – presupposes our obligation to preserve the fundamental right to life as an essential condition for fulfilling our duty as custodians of the mission given to us with our own existence.

For the believer, human life is a gift of God, and must be respected from its beginning until its natural end. Since the right to life is inviolable it is the strongest basis for the right to health and the other rights of the person.

4.2.2 The special protection of the disabled.

In every person with physical or mental health difficulties or intellectual disability we must see a member of the human community, a being who is suffering and who, more than any other person, needs our support and our signs of respect, to help them believe in their own value as human

³ Cf. LXIII GENERAL CHAPTER. The New Evangelisation and the New Hospitality on the Threshold of the New Millennium, Bogotá. 1994 . D.6.1.

persons. This is very important today because our society is showing increasing intolerance towards people with *disabilities and other challenges*.⁴

The Hospitaller Order must distinguish itself by virtue of its readiness to help as far as possible to bring about the practical and effective realisation of the principles of integration, participation, inclusion and personalisation. The *principle of participation* is contrary to the tendency to isolate, segregate or neglect the disabled. The *principle of inclusion* entails the commitment to rehabilitating the disabled by creating as normal an environment as possible. The *principle of personalisation* emphasises the fact that when dealing with the disabled their dignity, well-being and personal development occupy the pride of place, and that it is our duty to protect and foster their physical, mental, spiritual and moral faculties.⁵

4.2.3 *Promoting life in situations of poverty.*

In the New Evangelisation the Hospitaller Order must make visible the Gospel of life by making every possible effort to ensure that unjust, dehumanising structures are eliminated, and creating the possibilities for a dignified life wherever people are experiencing poverty, sickness, marginalisation, deprivation and abandonment.

By virtue of our discipleship of Christ according to the charism of St John of God, human life must be supported and promoted by the *service of charity* which is manifested in our individual and institutional testimony through different forms of voluntary service, social leadership or political commitment.

The service of promoting life must be carried out by promoting preventive activities and measures, helping invalids and rehabilitating people with disabilities. Whatever we do to help the disabled play a full part in life and in the development of the society to which they belong, and to create a social environment which fully accepts them as members of the community with special needs that must be met, will therefore never be sufficient. There will always be more to be done.

4.2.4 *Obligations and limitations on the conservation of one's own life.*

Life is a fundamental good of the person and a prior condition for the use of other goods, but it is not an absolute good. Life can be sacrificed for others, or for noble ideals which give life a meaning. Life, health, and all temporal activities are subordinate to spiritual ends.

We repudiate the notion of man's absolute and radical control over life, and we cannot therefore consent to anything which presupposes any total and independent right over life, such as the right to destroy it. At the same time we can affirm the 'useful' right of control over one's own life, but not the duty to preserve it whatever the cost. Life is certainly *sacred*, but it is equally important to consider the quality of this life, namely, the possibility of living it humanly and giving it a meaning. There is no duty to preserve life under particularly distressing conditions which demand disproportionate or futile treatments.

⁴ The WHO defines an impairment as "any loss or abnormality of psychological, physiological or anatomical structure or function", and a disability as "any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being" is a particular individual taking account of age, gender and cultural factors ".

⁵ In December 2006, the United Nations promulgated the Convention on the Rights of People with Disabilities. It identifies numerous rights and, in article 3 it summarises the following guiding principles: Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons; Non-discrimination; Full and effective participation and inclusion in society; Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity; Equality of opportunity; Accessibility; Equality between men and women; Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

4.2.5 *The duty not to place the lives of others in jeopardy.*

Human life is sacred because from the very beginning it was the fruit of the creative action of God and always remains in a special relationship to the Creator, its only end and purpose. God alone is the Lord of Life from the beginning to the end. No-one, under any circumstances, may claim the right to kill another human being directly.⁶ Since the Hospitaller Charism reaches out and welcomes all, the Order is always opposed to the death penalty regardless of the circumstances.

4.2.6 *Duties towards the resources of the biosphere.*

The protection of the integrity of creation underlies the increasing interest shown in the environment. The ecological balance and the sustainable and equitable use of the world's resources are important elements of just dealings with all the communities in our global village; they are also the object of justice to be shared with future generations who will inherit what we bequeath to them. The irresponsible exploitation of natural resources and the environment degrades the quality of life, destroys cultures and reduces the poor to abject poverty.⁷ We must foster strategic attitudes which create responsible relationships with the environment in which we live and which we share, and of which we are merely its stewards.

Since our structures are places in which we consume all kinds of material things, we can send out concrete and meaningful signs of our concern for the environment by setting up committees for this very purpose, giving pride of place to using biodegradable and recyclable materials, and sensitising everyone, Brothers and Co-workers alike, through courses and workshops.⁸

4.3 *Promoting health and alleviating pain and suffering*

4.3.1 *The duty to offer health education.*

Among the activities to improve the health of the population we have to stress the need to keep the public well-informed and run educational programmes which promote healthy lifestyles such as healthy diets, physical exercise, appropriate immunisation of babies, and reducing the risks to health which can be avoided, including the use of tobacco, alcohol and other drugs, as part of our work to promote the health of the population. This also includes avoiding sexual activities which increase the risk of contracting AIDS and other sexually transmitted diseases.

In many countries, healthcare education is one of the means used to reduce infant mortality and morbidity by breast-feeding and informing parents about appropriate nutrition and the risks of contaminated water.⁹

Those of us who work in healthcare have an ethical duty to foster the good of the patient at all times, and to incorporate that responsibility into a greater commitment to fostering and guaranteeing the health of the population.¹⁰

4.3.2 *Our preferential love of the poor.*

Our mission of making John of God present in a world of suffering and poverty, which is the world in which most of the world's population live, is particularly important because oppressive poverty – due to unjust social structures which exclude the poor – is generating systematic violence against the dignity of men, women and children and the unborn, which cannot be tolerated in the Kingdom willed by God.

⁶ Cf. JOHN PAUL II, *Evangelium Vitae (EV)*, 5.23

⁷ Cf. JOHN PAUL II, *Octogesima Adveniens* 21; JOHN PAUL II, *EV* 27, 42.

⁸ The New Evangelisation and the New Hospitality... *Op. Cit.*, 5.6.3, Concrete situation

⁹ Document of the World Medical Association, "Draft Declaration on Health Promotion, 10.75/94, August 1994.

¹⁰ *Ibidem*

“Our Order exists for the very purpose of evangelising the poor, accompanying them and assisting them in their sufferings in the style of St. John of God (...) We see some efforts being made to adapt our life and our structures to better serving persons who are sidelined from society: day hospitals, night shelters, care for patients with AIDS, drug addiction and terminal illnesses, the promotion of improvements in services and the environment in marginalised zones – from the bases of existing centres (...) These efforts always require very consistent action on the part of the Order if it is to present itself unmistakably to the poor as those who can provide support to alleviate hardship and provide assistance; so that by means of its life, its service, its mission of announcing and denouncing, it can exercise an increasingly greater influence in this field on the Church and the structures of society.”¹¹

4.3.4 and 4.3.5 transfer to chapter 5 on clinical ethics

(4.4 from this point onwards until chapter 5 the text has not been revised because it is not the responsibility of the Bioethics Commission)

¹¹ *The New Evangelisation and the New Hospitality...*, op. cit, 3.6.3.

5.

APPLICATION TO SPECIFIC SITUATIONS

5.1 Comprehensive care and the rights and duties of those in our care

Our contribution to society will only be credible if we are able to embody the progress made in technology and the development of the sciences. Hence the importance for our response in terms of care and assistance to constantly strive to be continually up to date in technical and professional terms.

On the basis of this, we must provide care that considers every dimension of the human person: physical, psychological, social and spiritual. Care that takes account of all of these dimensions, at least as a working criterion and as an objective to be achieved, can be deemed comprehensive or holistic.

Perhaps this is where the Order's Centres have managed to cultivate our best tradition. Their level of care has always been a feature which has made them stand out across the years.

The first Constitutions emphasised the way in which the sick were to be treated, and this is how things have continued ever since, giving pride of place to this aspect throughout history.

5.1.1 The humanisation of care

The concept of "humanisation" is a key element in the holistic, comprehensive care provided today. In the Hospitaller Order, particularly, this is the distinctive feature of its charismatic identity both because it has been implicitly present ever since St John of God first began his care ministry, and because it was so effectively relaunched in the 1980s by the Superior General at the time, Brother Pierluigi Marchesi.

While there is no doubt that a hospital which fails to keep abreast of scientific and technological progress cannot rest be complacent, and will find itself obsolete, it is equally true that science and technology also entail risks.

The continual development and the constant emergence of new working teams and techniques threaten to leave the human person on to one side, which includes both the practitioner and the patient or guest. Since in many cases, our work may relegate the patient or guest to a secondary and non-central role and, in the case of certain technologies or techniques, even to an unimportant role. This is refers to all the diagnostic services or information procedures where the practitioner played a vital part in the past to ensure that the work was done properly, whereas in many cases today, the patient's role is secondary or nonexistent.

But none of these developments are neutral with respect to the response of the person, and they do not desensitise people, even though there is a risk of becoming desensitised. The tendency towards a certain isolation and segregation, and towards technological tyranny may arise particularly against patients, who are passive subjects of all this professional activity: everything being done for the sick person, but without that sick person.

This is why it is vital to implement humanisation programmes in our Centres. We are referring here not only to the implementation of services as such, but to planning effective humanisation programmes.

We must succeed in ensuring that all the practitioners involved in providing assistance feel called to care for the patients or guests, as persons, and their families. This is what the humanisation of the St John of God Centres means, which ensures that all the healthcare workers work for the sick and with the sick, placing the best possible technical resources at the service of those in their care.

In this connection, increasing attention has been paid in recent years to a particular movement known as NBM (*Narrative Based Medicine*). It is not a movement contrary to but complementary to *Evidence Based Medicine*, combining the specifically scientific results of medicine with the human and personalised approach to the patient, taking account of all the patient's essential component parts. The patient's account of her illness and personal and family circumstances is therefore decisive for the purposes of adopting the most appropriate clinical approach. This approach, adopted in the form of a two-way narrative is therefore not only based on treatment of a "traditional" medical-therapeutic character that takes account of all the biographical aspects of the way the sickness is experienced by the patient. In this way, increased scientific skill must be linked to ever-increasing "human skills" by combining *high tech* with *high touch*, which is exactly what the Hospitaller Order has been saying since the 1970s about the humanisation of care.

Meeting personal (including spiritual and transcendental) needs is a key element in all welfare and health care work.

Man is a relational being, and it is to the extent that we are in contact with others that we consolidate ourselves as persons. It is by converting this contact into an encounter that we achieve the fullness of our relational dimension.

Hence the importance of meeting, listening, accepting, welcoming-in, and knowing how to channel all the positive and negative aspects that are present in every individual person who lives and perceives the needs of others.

Sickness, whatever external form it might take, isolates the person concerned, and expresses human limitations and weaknesses, and it is in this specific special circumstance that we place an explicit and implicit demand for mutual assistance.

Everyone experiencing their limitations and suffering look for someone with whom to share their plight, on whom to unburden themselves. Hence the need for all those who make up the Hospitaller Order - Brothers, Co-workers, Volunteers, etc. - to acquire, nurture and enhance the following qualities:

5.1.1.1 Outreach: to the new aspects and developments of society, to new criteria for action, to the new needs of mankind, and to other cultures. We are outreaching when we know how to welcome what society and the world are offering us, and to discern what is positive in this offering, to make it our own. The institution is also outreaching, if it knows how to adopt the same attitude, even though in this case it will require dialogue between the persons concerned, in order to be able to discern together what is positive for all.

5.1.1.2 Welcome and receptiveness. Welcoming-in and receiving those who arrive in a spirit of hope to give them confidence and trust in the individuals and the institutions taking care of them. This first contact is very important, and can open or close doors. In their state of need, this first contact with the sick and the guest is extremely important to them. Being in difficulty, feeling themselves accepted and welcomed is an essential means of instilling a sense of security and confidence in those taking care of them. We must be careful to ensure in particular that bureaucracy and administrative formalities do not become stumbling-blocks to the welcome we offer our guests.

5.1.1.3 The ability to listen and dialogue. Allow people to express their own plight, needs, fears, and to hear in us an echo of confidence and peace of mind, both at times of joy and in more difficult situations.

The sick and our guests must understand that none of this falls on deaf ears, but is listened to, considered, and borne in mind. They will only tell us what they are able to at that moment, possibly telling us everything about themselves.

There will also be situations in which the sick or our guests ask for or desire something that is not the most appropriate for them. On the basis of our own reflection we must be capable of

understanding and getting the sick and our guests to understand what we intend to do even in cases in which we may be acting according to different criteria altogether.

5.1.1.4 An attitude of service. Always being at the disposal of the sick, our guests, and their loved ones, always ready to give our technical skills, our knowhow and ourselves as persons, to serve them for their overall good.

We must not and cannot always do what the sick or our guests want of us, but from the attitude with which we treat the sick, they will be able understand whether we are acting for their good or for our own convenience.

5.1.1.5 Simplicity. Having the humility of those who know they are helping people in need with the main purpose of preventing a state of dependency from arising.

We must have the simplicity of those who are moving forward in search of the truth, and the good of all,.

5.1.2 The rights of our guests

The rights of our guests form part of the broader framework of fundamental human rights. From the point of view of human rights, the right to the protection of health is one of the so-called second-generation rights, namely, rights of an economic and social nature. With greater sensitivity towards this issue, in the 1970s there was an increase in interest in the rights of the sick and our guests, bearing in mind that as persons, the sick and our guests are entitled to the same universal rights, but in their case there are certain particulars due to their plight which demand greater sensitivity and solidarity. This has led to the production of national, regional and local declarations of rights.

The Order takes on board all these acknowledged and proclaimed rights, and in order to provide comprehensive care, it emphasises the following:

5.1.2.1 Confidentiality. Confidentiality comprises three intimately related values in the relationship of care: *privacy*, *secrecy* and *trust*. Respect for individual persons demands the respect for the patient or guest's privacy,¹² namely, that particular area in which everyone can have the opportunity to affirm and reinforce their own identity. Respect for the privacy of each person makes it possible for a wide variety of different individuals to live together in society. The veil of confidentiality and privacy safeguards mutual respect, and opens up the possibility to trust, as the path to accede to the private sphere of other people.

Mutual respect and trust open up the way to the right to communicate one's own secrets, knowing that they will not be disclosed. This is the obligation of professional secrecy which is taken for granted and is implicit in the commitment not to divulge to others what one learns in the course of one's professional practice.

The obligation to secrecy coexists with the obligation to disclose a secret only when there is no other way of preventing damage and harm being unjustly caused to another person or to society, for example, to prevent contagion or another evil from which society could not free itself unless it knew the secret.

The increasing specialisation and technological sophistication of medicine is increasing the number of cases in which medicine is practised as a team. This creates *shared confidentiality*, which demands special attention by everyone involved in order to guarantee that guest's or patient's privacy is not violated.

¹² Some prefer to use the term *privacy* to refer to a more global, comprehensive set of aspects of the human personality which, considered separately, might not have an intrinsic value in themselves, but linked together in a coherent manner, reflect a picture of the personality of the individual which the latter has the right to keep confidential.

Every healthcare worker in hospitals or healthcare and social residences and facilities must be sensitised to understand the ways in which the right to privacy and confidentiality can be violated. One only has to think of conversations in public places about guests or patients, or ease of access to clinical records by unauthorised personnel. Particular care should be paid to protecting the lists of patients whose diagnosis or treatments are held in computer files.

In order to facilitate respect for the guests' or patients' privacy, our Centres must, as far as possible, have fixed or mobile facilities (which might be individual bedrooms or private rooms, or curtains or screens) so that patients can be isolated when needed. Account must also be taken of the age and the seriousness of the illness of those sharing the same room or ward.

Patients and guests may ask to be left alone or with a person of trust when they are examined by their doctor, or when they receive nursing care. In this way, they can talk privately with the administrative staff. One must also remember that any hospital, and particularly university or teaching hospitals, are training centres, and that their cooperation is vital in this regard.

5.1.2.2 Telling the truth. The patient's or guest's right to know the truth goes hand in hand with the right to confidentiality that we have just examined. They are complementary rights and provide the most solid basis for the necessary trust to be established in the doctor, but both may clash in terms of the fundamental rationale of the doctor-patient relationship: restoring the patient to health.

The first point to which priority must be given is the right of the patient or guest to be told the truth about their state of health, but not at the expense of what it is appropriate to the patient as a person. Sometimes there are reasons of genuine love which make it advisable to remain silent: the truth might cause unnecessary harm.

A number of factors influence what it is appropriate to tell the patient or guest: the assessment of the patient and his/her inner strength, personal convictions and mental balance, and also the type of relationship existing between a given physician and a given patient. Neither must the economic, family and social circumstances of the patient, following the medical consultation, be neglected. However the diagnosis and the prognosis take on particular importance.

When it is necessary to tell a patient that death is inevitable and drawing close, this must be done in such a way that they can fulfil themselves in the final act of their life. This duty presupposes that the patient is capable of taking on and adequately expressing their role at that decisive moment in their existence. Leaving the patient a glimmer of hope ('a little open sky' as someone has put it) may help the patient, but it should not be forgotten that giving up false hopes can give another type of hope which enables us to accept the truth with greater ease and thereby wholly fulfil ourselves as human persons. This also occurs in the case of people who do not believe in a future life, but who have managed to give their own lives sense and meaning in relation to others.

The patients and guests are the *holders of the right* to know the truth, provided that they are adults and their own masters. When patients or guests do not have the capacity to take on this responsibility because they are not sufficiently mature or for any other reason, the information must be disclosed to those who can or must take decisions on their behalf, as their guardians or as the persons most concerned for their good and their welfare. If the patient or guest has the capacity, the only information that should be given to their relatives and loved ones is what we reasonably believe the patient or guest would wish them to know.

5.1.2.3 Autonomy. Enhancing and respecting autonomy, particularly in the field of medical care, is one of the great achievements of the modern world. Until only a few decades ago, there was a strong sense of paternalism in the relationship between the doctor and the patient, or with the guest, with the result that it was generally the doctor who decided, and the patient or guest who trustingly followed the doctor's advice, aware of not being either competent nor sufficiently well-informed to be able to choose the best course of action. The patient or guest was also fully convinced that the doctor would always act in their best interests.

Today's 'post-modern patient' no longer reasons in this way. They are now aware of their 'rights', including the right to life and the protection of health which are certainly their priorities. And they are also aware that they are not only the holders of these rights whose defence cannot be delegated to others, at least while they are in a position to take informed decisions themselves.

But this change in attitude has not been painless, and even though the former paternalism is no longer acceptable today, it has often been replaced by an extreme form of '*contractualism*', where the relationship between the physician and the patient is seen merely as a 'contract' requiring both parties to comply with the terms and conditions. Obviously, this polarisation can only be superseded by establishing a *therapeutic relationship of trust* in which the doctor cooperates with the patient for his higher good, respecting mutual decisions and choices. A fundamental condition for this to occur in the best possible manner is that a very clear understanding must exist regarding what is meant by patient autonomy.

According to a classic interpretation a decision may be considered autonomous when it meets three conditions. The first is *intentionality*. In other words it must be an absolutely 'voluntary' choice and not merely a 'desired' choice. Secondly, the person must *know* what is being decided. Naturally, all this raises the question of the problem of telling the truth to the patient or guest, which was discussed in the previous section, to which the reader is referred. Lastly, it must take place in the *absence of any external constraints*. This means that there must be no form of coercion (not even the coercion that might stem from the authority which the physician may have over the patient or guest, or the fear that the patient or guest might stop taking the treatment) nor manipulation (such as changing or manipulating the truth, even if this is done considering that it is in the patient's or guest's best interests). These criteria often include the absence of 'persuasion', even though we believe more prudently that a balanced and respectful attempt at persuasion might even be a duty, whenever it is really intended for the good of the patient or guest.

In practical terms, of course, these criteria that are inherent in the autonomy of the patient or guest are fully manifested in their *consenting* to the action taken by the physician, whether this is diagnostic or therapeutic. For a more organic way of obtaining consent it might be advisable for the Houses in the Provinces to produce specific forms for use in clinical practice in the Centres. It is very important for all the health care workers to understand that the request for consent is not a legal procedure to protect the doctor but one of the rights of the patient or guest, and as such it places specific ethical duties on the health care workers themselves.

Lastly, we should reflect on the limits to autonomy. Even though this is the first principle of bioethics, and the one around which most bioethical problems hinge today, it cannot be considered an absolute principle, or be treated as if it were paramount in respect of the others. There are objective limitations on the autonomy over choices such as, first and foremost, one's own life, and this cannot be left unconditionally and immediately to the choice of the guest or patient. This would legitimise suicide of all kinds. What has to be considered, instead, is that in relation to the sick and the guests the supreme value to be respected is not their autonomy, but their rights, which certainly includes their autonomy.

Moreover, within the bounds of autonomy we also have to include religion and culture. With regard to religion, then may be conduct deemed illicit according to the individual's own religion alone, while in other cultures, autonomy does not always have an individual character, but takes on a collective dimension. The individual is considered to form part of the group; it is the group which holds full decision-taking powers in respect of the individual concerned.

5.1.2.4 Freedom of conscience. The right to freedom of conscience which is clearly enshrined in Article 18 of the *Universal Declaration of Human Rights* and in most Constitutions of modern States is demanded by the ethical dimension of the human being and the realisation of their own existence as a gift and a project to be implemented. Everyone is therefore entitled to respect for their ideas, and their philosophical, ideological, political and cultural choices, provided that they do

not infringe any fundamental human rights. This has become particularly important today faced with multiculturalism and the wide variety of ethical options that exist in contemporary society.

This sphere relates in particular to the religious dimension of existence. We should remember that the declaration *Dignitatis Humanae* of the Second Vatican Council began by stating that ‘the person has a right to religious freedom’.

The exercise of this freedom is naturally dependent upon the general principle of personal and social responsibility, the fact that every individual or social group is obliged to take account of *the rights of others and their duties* to others and to the common good. These restrictions take the form of the need for a legal order which provides specific protection for this religious freedom and the defence against unjust proselytism.

Every person and the whole Church is entitled to bear witness to their faith. The right to religious freedom includes the right to bear this witness while always respecting the justice and the dignity of the conscience of others. But ‘proselytism’ is a corruption of this witness, because it comprises any form of abusive and impertinent conduct in the exercise of Christian witness which threatens the religious freedom of others. The main attitudes to be condemned, according to the World Council of Churches and the Secretariat for the Unity of Christians, are:

- any kind of physical, moral or social pressure leading to the alienation or the deprivation of personal discernment, free will and full independence and responsibility on the part of the individual;
- any material or temporal benefit openly or indirectly offered as the price for accepting the faith of the person bearing witness;
- any benefit resulting from a state of need in which the person receiving the witness may be, or resulting from their weak social status or lack of education, in order to convert that person to the other's faith;
- anything that might give rise to suspicion regarding the other person's good faith;
- any unjust or uncharitable allusion regarding members of other Christian communities or non-Christian religions in order to attract followers;
- any offensive attacks which wound the feelings of other Christians or members of other religions.

5.1.3. Duties of our guests

While patients and guests have rights, they also have *duties*, even though these have been less thoroughly elaborated in bioethical and practical terms.

5.1.3.1. Respect for the institution and its principles. The Hospitaller Order's health care facilities are declaredly Catholic denominational institutions. For this very reason, its mission, as the expression of the universal mission of the Church, is available to all without any form of ethical, ideological and religious discrimination. But at the same time, even those who do not share the Catholic faith or the principles on which the care it provides is based, are duty-bound to respect the spirit driving all these facilities. They must therefore avoid any conduct which is in blatant conflict with the principles professed by the Order. This clearly does not mean that they may not complain or claim against it in the event of negligence or wrongdoing they may have suffered (but which remain such, regardless of their religious faith) nor that they are not entitled to full respect for their own religious allegiances, as has already been affirmed in relation to the patients' and guests' rights.

5.1.3.2. Respect for the health care workers. The health care workers who assist the sick, in whatever capacity, are also entitled to have their professionalism, dignity, honour and their work

respected, above all when this is particularly burdensome because of the post they occupy. They are therefore duty-bound to respect this, knowing at all events that the health care workers are devoting themselves to looking after people in need of care. If this may not appear to be optimal sometimes, (except in cases of malpractice), the understanding which patients and guests demand be shown towards them must also be shown towards the personnel. It is true that this is an asymmetrical relationship, but the personnel are people, with their own weaknesses, tiredness, family problems, financial and work problems, anxieties, concerns and the discomfort that can often be reflected in their relationships which should always be cordial and empathetic. It is precisely the esteem and understanding received from the patient that can help them to perform their work in the most humanising manner possible.

5.1.3.3. Respect for the patients and guests. Individual patients and guests are not alone in making use of the healthcare facility, and must therefore take account of the other patients and guests who share it with them. They must therefore avoid disturbing them when they are resting, particularly in the night hours, compatible with the demands of their treatment. They must avoid making a noise and disturbing others during visits from their relatives, or raising the volume on the television, or doing anything else that may annoy the other patients and guests. But in addition to these "negative" indications one should not underestimate the positive ones. The joint presence of patients and guests sharing the same facilities is also a huge psychological resource, and is therefore a therapeutic aid. Establishing good relations, particularly in long-term units, can be helpful to make it easier to accept their stay in hospital, which is always distressing, and to enable patients and guests to help one another while they are in care.

5.1.3.4. Respect in the clinical approach. Relations between the healthcare worker and the patient or guest in the course of treating them entail the use of a series of clinical instruments of various kinds: talking with the patient about their clinical history, lab tests, diagnosis by imaging etc. In so doing the guest or patient must fully cooperate with the care-givers acting with due diligence, which means always bringing their clinical records with them, carefully looking after them (without creasing or soiling them etc), not concealing them to see whether the doctor is able to work properly without them, not placing their relations with the doctor on the same plane as relations with the Internet where they can find any information they need, and diligently complying with the doctor's treatment instructions.

5.1.3.5. Respect for the premises. Patients and guests quite rightly want the hospital environment in which they stay to be "hospitable", with clean and welcoming rooms, efficient services and common areas for their relatives, etc. For this reason they should be the first to show concern for keeping the premises clean and in order. The "public" facility is not something that belongs to no-one, but it belongs to everyone. As such, the patients should not only treat it with care, as if it were their own home, but indeed with even greater care because the common areas also have to be used by other people. Moreover, the need to show this respect involves the other patients and guests living there at the same time, who must be encouraged to do the same, almost "handing over" the facility to them in the same optimum conditions in which they found it. This care and attention applies to the way the furniture is used, keeping the rooms clean (as far as the patients' and guests' responsibility is concerned), not to scribble on the walls, to treat the lawns, where they exist, with respect, not to ignore conduct which could prove damaging (leading to fires, flooding, etc).

5.1.4. Children's and adolescents' rights

When addressing the question of patients' and guests' rights, the specific rights of children are of particular importance. These include the right to be given information on their health, the right to determine their own state of health (within the bounds, and in the manner, set out in greater detail in the following section dealing with consent), the right to confidentiality of their clinical records, the right to religious freedom and physical integrity. It is also essential for a child admitted to hospital to

be accompanied by relatives, and also be able to continue their schooling. With respect to these rights, here are a few of the main emerging issues:

5.1.4.1. Children's consent and assent. In most countries, consent to, and refusal of, treatment is the responsibility of the people exercising parental authority over the child, namely, their parents or, in their absence, their legal guardians. But this does not mean that the child has no right to decide for itself or must not be asked when treatment is proposed. In strictly legal and forensic medical terms, in countries in which even emancipated children are subject to parental authority the child may only *assent*, which does not exclude the consent of the parents, but in all instances we are duty-bound to take account of the child's preferences, desires and wishes. Obviously this has to be proportionate to the child's ability to understand, linked among other things to the child's age. As the Oviedo Convention (1997) provides, the child's opinion must be taken into consideration as a factor whose importance will depend on the child's age and level of maturity¹³. The request for assent is particularly important when trialling drugs. It is possible to test drugs on children provided that the child will at least potentially benefit, and that any harmful effects are acceptable.

5.1.4.2 Extremely underweight newborns. In the most scientifically advanced Centres in the Order, one problem that will arise with increasing frequency has to do with procedures for the resuscitation of pre-term and extremely underweight babies (< 24 weeks and 500 gr.) which until not long ago were classified as 'miscarriages'. This problem refers mainly to the outcomes of resuscitation procedures which, while enabling babies weighing only a few hundred grams to survive, may also leave them with permanent disabilities. According to the general criteria of proportionality of treatment, we are ethically bound to do everything which is "proportionate" to the situation before us, avoiding futile therapy.

5.1.4.3. Conflicts of interests. When caring for children and adolescents, their best interests must also be to the fore. There are numerous situations causing conflicts, whether in the practice of ordinary daily care or those relating to the more sensitive and clinically more complex situations which can create a conflict of interest between the parents and the children. For example, a more painful, but quicker and more "convenient" treatment for the relatives, corrective plastic surgery merely to satisfy a patient's narcissistic demands, the use of sedatives which are clinically unnecessary, and forms of withholding or conversely increasing treatments which have no medical justification.

5.1.4.4. Clinical trials. Here again, the interests of the child or adolescent must always prevail. In paediatric care, clinical trials differ from those conducted on adults. They may refer not only directly to the person taking part in the trial in the case of adults, whereas in the case of children and adolescents there must always be possible benefit to the patient. In randomised studies which also make provision for the enrolment of healthy participants, no child or adolescent enrolled with their consent may be subjected to any dangerous or invasive treatments. In all instances, even though in purely legal terms a child or adolescent may not have the capacity to give their valid consent, which is always given by those acting *in loco parentis*, the child's or adolescent's *assent* must be formulated within the limits and in the forms permitted by their capacity. Without it, even if the parents consent, the trial must not be run.

5.1.4.5. Futile treatment. Problems relating to futile or excessively invasive treatment of children and adolescents must be addressed. While such treatment is controversial in adults, it is even more questionable in children and adolescents subjected to futile treatment which will not produce a positive clinical outcome. Even though the parents might decide to pursue such treatment out of love for their child, it is not always really in the child's interests but is merely to give the parents the illusion of having done everything possible for the good of the child's life or health.

¹³ Council of Europe, The Convention on Human Rights Biomedicine, Oviedo 1997, op. cit 6.2

5.1.4.6. *Adolescence.* Today, teenagers have not only taken on a radically different role from what they used to have, but they are most risk-prone in respect of certain issues such as dependencies, sexually-transmitted diseases, unwanted pregnancies, eating disorders, etc. Furthermore, even if they are still subject to parental authority (although the law varies from country to country, according to their age), under certain conditions they can authorise certain actions such as organ donation, or abortion. The particular psychological sensitivity and issues of this age group, their need for autonomy, religious crises, family problems etc. demand that all the people who deal in any way with them must have a special sensitivity and particular human skills, as well as a thorough familiarity with the younger generation and their demands, questions and critical traits. They must therefore be given clear and comprehensible explanations on the diagnostic and therapeutic procedures to which they may be subjected, and their rejection of any proposed treatment must also be recognised and respected.

5.2 Specific problems regarding our care work

5.2.1 *Sexuality and procreation*

5.2.1.1 *Responsible parenting.* Human procreation is the way through which God cooperates with the couple who freely place themselves at God's disposal as an instrument for his creative act through generation. This explains the high value of human procreation which, by this token, is entrusted to the couple's responsible parenting.¹⁴ This procreative responsibility means that the couple must be very attentive to the two-fold significance of conjugal sexuality: to unite them and to procreate. In the performance of this important task, the couple will have to be guided by the Word of God and the teachings of the Church which they responsibly take upon themselves in the unique singularity of their own conscience.

In the Order's Centres encouragement must be given to all those structures which can encourage real procreative responsibility, which includes adequate *counselling*, according to the specific procedures and methods that are appropriate to the healthcare and cultural situations in each country.

These criteria will also form the basis for the professional services offered by the health care workers to both outpatients and inpatients and guests.

5.2.1.2 *Voluntary abortion.* Human life is a universally recognised value in itself, even though it is perceived with different historical and cultural sensitivities. Respect for life and protecting it lie at the basis of all the health care professions and organisations.

Protecting life runs throughout the whole of life from its beginning until its natural end, independently of the procedures and circumstances in which conception takes place, or of the state of health before and after birth, its expressions in terms of relationships and social acceptance. Indeed every situation in which an existence is at risk, following the example of St John of God, constitutes a reason for individual and community commitment to preserve and protect the gift which God has entrusted to human care.

When we say that for us human life is inviolable, we are laying down an ethical principle with which compliance is demanded, independently of the complex theological issues relating to the moment of its 'animation' (that is to say the infusion of the supernatural soul, whether this occurs at conception or subsequent to it). According to the balanced and prudent views set out in *Donum Vitae* and *Evangelium Vitae*, human beings must be respected 'as persons' from their conception

¹⁴ JOHN PAUL II, *Evangelium Vitae* (EV), 44.

because they possess the dignity that is vested in the human person from the moment of conception.¹⁵

It is, nevertheless, necessary to ensure that our disapproval of voluntary abortion does not lead us to despise the person who has an abortion. Indeed, with Christian charity, our works should become Centres not only to welcome in life, but also to 'rebuild' an existence which is often profoundly upset as a result of having been through an abortion. Not only must we ensure that our condemnation of the wrongful act does not lead to condemning the wrongdoer, but we must assist that person, through love, to become aware of that error while trusting in the unfailing pardon and forgiveness of God.

The unlawfulness of procured abortion does not mean that pharmacological or surgical measures may not be adopted to safeguard the health of the mother which may *also* have the effect of leading to the death of the foetus, provided that the latter is not the direct intention, and that it is not achieved *through* the operation or pharmacological treatment, and that the measure cannot be postponed.¹⁶

5.2.1.3. *Conscientious objection.* The inviolability of human life not only prevents voluntary abortion being performed in the Hospitaller Order's centres but also other types of intervention which suppress life. The personnel working in these centres are therefore required to be conscientious objectors. This consists of refusing to perform a statutory obligation whose effects are considered to be contrary to one's own ideological, moral or religious convictions. In the field of health care, this applies not only to abortion but also to certain assisted procreation practices, euthanasia and certain measures suspending life-maintaining therapies. Conscientious objection is permitted in some legislations governing its scope and its application. However, as a mere "conscience clause" it can also apply to any situations in which the physician feels unable to comply, in conscience, with certain statutory requirements. In this case, the physician accepts full responsibility for so doing which also includes legal liability. By its very nature, conscientious objection is always a matter for the individual. Possible local agreements and, more recently (2010) a resolution adopted by the Council of Europe, provide the possibility for "institutional" conscientious objection, permitting a whole healthcare facility, and not only its individual staff members, to be exempted from performing actions which are against the specific identity of the facility.¹⁷

5.2.1.4. *Prenatal diagnosis.* Prenatal diagnosis today is one of the most sophisticated tests performed, and in the future it is bound to be more widely practised and be methodologically perfected. It can be performed with non-invasive methods such as morphological echography, or echocardiography; or with invasive methods (amniocentesis Chorion Villus Sampling) and biochemical tests (tri-tests, etc.). Very often some of these are used in combination.

Amniocentesis, when immediately applied, is not immune from the threat of an erroneous approach in principle by intending it to be used to justify an abortion. Putting the problem in these reductive

¹⁵ Congregation for the Doctrine of the Faith, *Dignitatis Personae* (2009) 5.

¹⁶ Pontifical Council for the Pastoral Ministry of Health Workers, *Charter for Health Care Workers*, Vatican City, 1995, #142.

¹⁷ Cf. Benedict XVI. Audience for Catholic Pharmacists at their 25th International Congress. 29.10.2007. Resolution 1763/2010 of the Council of Europe states, "No person, hospital or institution shall be coerced, held liable or discriminated against in any manner because of a refusal to perform, accommodate, assist or submit to an abortion, the performance of a human miscarriage, or euthanasia or any act which could cause the death of a human foetus or embryo..."

In December 2011, the Order's General Bioethics Commission publish the document entitled *Conscientious Objection* (available on the Order's website) which sets out not only the general principles but also a detailed analysis of matters relating to the so-called "conscience clause", pharmacists' conscientious objection to prescribing the "day after pill" and cooperation in evil, etc.

terms is a radical betrayal of the spirit of service to people which scientific research embodies to such a high degree. The greatest expectations, however, lie with the prospects of intrauterine therapies which already beginning to emerge, and for which prenatal diagnosis is the indispensable precondition. Particular care must therefore be taken to ensure that prenatal diagnosis procedures are not designed exclusively for abortion purposes in the event that foetal malformations are identified. Indeed a positive commitment to life and to welcoming the weakest and neediest, which includes a malformed person, require us to give it a more concrete and practical welcome, faithful to the Charism of St John of God. This is all the more necessary because the dominant culture and the policies of many governments are tending to deny life to people who are in some way "imperfect". The possibility of performing these diagnostic tests in the Order's centres requires us to ensure that the centres themselves should set up experienced counselling centres for couples and families in difficulty because of the birth of a malformed child. Recently, prenatal diagnosis has also been used, particularly in certain countries, to destroy female foetuses, even if completely healthy.

5.2.1.5. Interceptives and contraceptives. These are two types of drugs whose effect is to prevent implantation of the embryo or to provoke its detachment in the initial phases of implantation.

RU 486 is the acronym for a drug which, in the early stages of pregnancy, can detach the embryo that is already implanted in the uterus lining. For a moral assessment, then, that judgement will be no different from the one used regarding the voluntary interruption of pregnancy. Furthermore, abortion could become trivialised to a certain extent by classifying this drug as an "abortion pill" and make women feel alone once again considering that the abortion as such can also be procured outside the hospital environment.

The term "interception" refers to all the methods intended to prevent the implementation of the embryo after "unprotected" intercourse. To be effective they have to be used within 72 hours of intercourse. The most common form of interception is the so-called "morning after pill". The latest studies are not sure whether the action is, in fact, interception because it may also be contraceptive for all intents and purposes.

5.2.1.6 Assisted reproduction. There are many childless couples who resort to assisted reproduction techniques as an effective means of overcoming a problem which is not of their making.

No Centre in the Order may offer this service unless it is highly qualified to do so and legally recognised for this purpose. In this case we consider it ethically acceptable to help couples, using assisted reproduction techniques, to enable their sexual intimacy¹⁸ to have a procreative outcome, using the couple's own gametes, and respecting the life of the embryo.

Where public health policy requires other types of action, acceptable solutions must be found or alternatives chosen. The Ethics and Bio-ethics Committees can be an excellent source of help here.

5.2.1.7. Female genital mutilation (FGM). This is an ages-old practice, but only recently has it caught the attention of public opinion. It refers to several types of action, sharing the common feature of mutilating the woman's external genitals. In addition to the immediate damage caused (infection, haemorrhages, algogenic shock etc), it can also have serious long-term sexual and reproductive effects on the woman. But it is above all in psychological terms that FGM can be seen as being wholly valueless because it constitutes a brutal and unmotivated form of female domination. In addition to robustly condemning this practice, we must therefore pay particular attention to providing medical treatment to women who have undergone this operations whenever they come to the Centres of the Order, not only in the regions where this is practised, but also in other regions where FGM victims may have migrated. Furthermore, in the areas where women are most at risk, measures must also be taken to provide such women with adequate hospitality as well as psychological and human accompaniment.

¹⁸ Cf. Charter for Health Care Workers, 21

5.2.1.8. *Gender reassignment.* In some centres in the Order ethical/clinical problems have been posed in the case of transgender persons seeking various types of medical or surgical operations (mutilation or reconstruction) in order to adapt their somatic sex to their psychological gender. There is no single opinion on such cases. For in terms of respect for the anatomical integrity of the individual, such operations are seen as damaging the body for reasons other than the treatment of a pathological condition. But with the broader consideration of the overall welfare of the patient or guest, to which all our care must be devoted, it may be seen as the restoration of a kind of lost unity, removing what the patient or the guest consider to be an irreversible and untreatable psychosomatic laceration.

5.2.2 *Organ donations and transplantation*

5.2.2.1 *Organ transplantation.* The possibilities offered by modern transplant technology today constitute one of the greatest ethical challenges of our age, and invite us to adopt a new dimension of interpersonal solidarity. Transplantology today offers numerous options:

Transplants from a dead organ donor. This is the most common and widespread form. All men and women, and *indeed* all Christians, should consider that donating their organs after death is a duty. The Hospitaller Order supports the efforts of the whole community in advocating, disseminating and embodying a 'donation culture'. Apart from the legal aspects which require more or less explicit consent to the removal of one's organs after death, this dimension of donation should never be lost from view.

Since the Order has a double dimension, as a Church entity and as a healthcare structure, it can therefore help to overcome this reluctance. The reverence due to the dead, with which Christian piety is richly imbued, must not become a cult of the corpse. There nevertheless still remains one unlawful area for particular types of transplantation which it might become possible to perform in the near future (and which might pose problems for the more advanced Centres in the Order), such as brain, gonad and face transplants. For these are operations which, to some extent, transfer a person's identity and not merely an organ.

Transplantation from a living person. A different problem arises with regard to transplants between the living. Even though it is an extremely generous and sometimes heroic act to donate one's organs to another, precisely because it is an extraordinary act, it cannot be given the same ethical status as donating one's organs after death. It is therefore one of those extraordinary acts which one is not obliged to perform in the strict sense of the term, but which are nevertheless an expression of great and extraordinary generosity. In a number of countries, legislation reserves organ transplants only to members of the same family or with a few exceptions, to people with particular bonds with the patient (partners, etc). Only recently has it become possible to envisage offering this possibility to unknown donors, but there are a number of ethical reservations.

Transplantation from animals. First of all it must be made clear that there is no a priori reason for considering that such transplants are, in themselves, unlawful. However there are certain specific problems. The first one might be of a psychological and emotional character, which may be fairly easy to come to terms with, when the recipient has to live with an animal organ inside. Secondly, a general issue could relate to the use of animals for this purpose, for which there are quite a few opponents. Even though the life of an animal is worthy of protection, however, in a hierarchy of values, animal life is subordinate to human life and in the case of conflict between the two, or at a moment of crucial necessity, a healthy anthropocentric approach gives pride of place to the human species over the animal species.

5.2.2.2 *Ascertaining death.* For the purposes of removing organs from a corpse, the delicate problem of ascertaining brain death arises for most transplants, even though in itself this diagnosis does not apply to the case of transplants alone. Quite clearly, it is only possible to remove an organ

from a person who is truly dead. For this reason there are various rigorous criteria, which have been codified in most legislations. There are those which accept "brain-death" as a criterion validated by the international scientific community and fully accepted by the Catholic Church. An individual is deemed dead when, according to certain clinical and/or instrumental parameters, there is no longer any activity in the cerebral cortex and in the brain stem.¹⁹ For *death is a process*, and not an event, and the end of one's earthly existence is not therefore the death of *the whole organism* (because some components may continue to live on even after the brain ceases to be active) but is the death of *the organism as a whole*.

5.2.3 *The chronic sick and those in an advanced stage in their illness*

5.2.3.1 *Euthanasia*. Respect for life which begins from its beginnings continues throughout the whole of existence until its natural end.²⁰ The expression 'euthanasia' means the act of procuring death using procedures which deliberately and voluntarily cause it (improperly called *active euthanasia*) or by omitting or refraining from procedures which might prevent it. The latter case is equally improperly called *passive euthanasia*, which is an ambiguous and improper term, for it is either the deliberate suppression of human life (by commission or omission) or it is merely the avoidance of useless aggressive therapy to no purpose (in which case it is not euthanasia). The term *assisted death* or *suicide* is being increasingly used to indicate euthanasia at the request of the patient and to a certain extent this places the burden of responsibility entirely on the patient. But in reality it does not remove the physician's responsibility and liability for directly cooperating in it.

Applying the same principle of double effect already used in relation to abortion, it is not euthanasia to take action to improve the pathological status of an individual (for example to suppress pain) when it is *also* likely inevitably, but not deliberately, to lead to anticipating death.

The duty to guarantee everyone a dignified human death means, at all events, that every person *must be treated* until their last moment in life. In view of the radical difference between *curing* and *caring*, there are no sick people that cannot be cared for, even though there are those who cannot be cured. Appropriate feeding, cleaning wounds, bodily hygiene and suitable environmental conditions are inviolable rights of every patient, who may not be deprived of them until the very final moments of their existence.

5.2.3.2 *Advance instructions regarding treatment*. These are set out in a document, known as a living will, which sets out the wishes of an individual to ensure that his or her values and convictions are respected if, as a result of an injury or of illness, they were to become incapable of manifesting them. More specifically, in the living will people request compliance with their right under those circumstances not to be subjected to disproportionate or unnecessary treatment; that the death process should not be unreasonably prolonged, and that suffering should be alleviated using appropriate drugs, even if the effect of this might be to reduce their life expectancy.²¹ Moreover, a proxy may be appointed to take decisions whenever the patient is no longer able to do so personally.

Formulated in this way and as a declaration of intent, these advance instructions are certainly good and to be recommended. In the countries with legislation that permits this, a broad section of society is insisting, with good reason, to be given the statutory protection of a living will.

The Church cannot accept any action to provoke death, even if this is the will, freely expressed by the person concerned. Limited freedom to dispose of one's own life through the intervention of third parties in the event of an incurable and permanent disease or incapacity, to the point of directly causing a person's death, and the lawful rejection of disproportionate treatment, marks the

¹⁹ Ibid, 129.

²⁰ Cf. EV, 57

²¹ Cf. Congregation for the Doctrine of the Faith, *Declaration on Euthanasia*, 5 May 1980, III- IV

difference between advance instructions which are acceptable for Catholics, and its other forms of expression.

The problem of assisted feeding, which in itself should be considered an ordinary and proportionate procedure, because it cannot be governed by any rules set out in advance, remains an open issue.²² However, many people are of the opinion that the purely medical ways in which this is performed could be equated with a therapeutic measure.

5.2.3.3. *Vegetative state.* The vegetative state is a condition following a fairly long period in a coma in which the vegetative activities are still being controlled by the brain while the cortex activities (consciousness, voluntary movement etc) are absent. Sometimes a patient can "awaken" from this condition, which may have lasted for several years, leaving deficits varying in gravity, according to the patient's condition. But awakening becomes increasingly more difficult as time passes from the event which produced the coma. After a few years this is possible only exceptionally. Any intervention on the patient in a vegetative state is therefore performed on a biologically living individual, albeit in a purely vegetative state, and without any subjective relationship with the surrounding environment. All treatments must therefore be limited to ordinary and proportionate therapies avoiding any futile or excessive treatments.

5.2.3.4. *Palliative care.* We may say that from the very beginning man has practised palliative treatment whenever dealing with the 'terminal' phase of an illness, supporting it with all the remedies possible but also helping, comforting and accompanying the dying until the last moment. Today we have a more elaborate idea of this kind of treatment, together with a more highly structured system to deal with it (in hospices, palliative treatment units, etc.) which enables us not to leave people suffering from an incurable disease to their own devices. Palliative care is therefore 'total care' offered in a global system of relations providing aid to meet all the patient's care requirements.²³

Palliative care is applied not "when there is nothing more to be done" but it is precisely *what is needed to be done for that particular patient*. It will certainly not cure the patient, because that is impossible. But it involves a whole series of treatments (sometimes technically very demanding) which will guarantee a good quality of life for the time remaining.

One particularly sensitive phase is the process of moving from treatment to palliative care. What has been called *simultaneous care* is particularly important in this phase, in which two types of treatment are applied – whether therapeutic or palliative – thereby offering the benefits of both with a net benefit in terms of a clinical improvement on the one hand, and a better quality of life, on the other. This dual approach includes the possibility of taking part in clinical trials, etc. This enables the patient to retain the possibility of receiving further treatment opportunities, while at the same time it does not necessarily require the patient to choose between two different types of care.

In view of these considerations, all the institutions of the Hospitaller Order dealing with patients in an advanced stage of their illness should as far as possible provide palliative treatment units to make the final phase of a patient's illness bearable, while at the same time providing patients with adequate human company.

5.2.3.5. *Palliative sedation.* This is also known as "pharmacological sedation" or, improperly, "terminal sedation" and is a therapeutic procedure to be used in every situation in which the final phases of life are accompanied by pain, anxiety or fear which cannot be otherwise overcome. Even though it is better to live this final phase in one's existence with complete lucidity and an awareness of what is happening, in persons for which this is only a source of suffering, treatment can be agreed with the patient, but without any euthanasia-oriented intentions. If this treatment leads to a

²² Cf. Congregation for the Doctrine of the Faith, *Responses to certain questions of the United States Conference of Catholic Bishops concerning artificial nutrition and hydration*, 14.09.2007.

²³ Cf. EV 65.

possible acceleration of the process leading to death, this will always be lawful, if the conditions of the so-called principle of double effect are applied.²⁴

5.2.3.6. *Terminal foetus*. This expression is used to refer to all the pathological conditions of a foetus which are incompatible with life, whether genetic or due to malformations (anencephaly, renal agenesis, certain chromosome diseases, etc.) or as a result of mother-foetal disease (serious retarded growth, placenta or umbilical cord disease, etc.). These conditions raise sensitive bioethical issues which always refer to respect for human life, and hence the rejection of abortion even when it is labelled "therapeutic", but in some cases the possibility of an early delivery without directly killing the foetus which is bound to die very shortly thereafter.

5.2.4. *The ethics of therapy*

5.2.4.1 *Proportionality of treatment*. Insofar as our hospitals are intended to promote and protect health, they cannot consider death as something to be psychologically displaced, but view death as an integral part of the course of life which is particularly important for the full and transcendental fulfilment of the patient. Consequently, every patient is entitled to the right not to be prevented from taking responsibility for the event of his or her own death, and indeed must be helped to do this in accordance with their religion and their sense of life. This means that unless it is truly and urgently necessary, the truth must not be concealed from the patient or denied to the patient, and the patient must not be prevented from enjoying their usual relationships with their families, friends, religious and ideological communities. This is the only way in which the humanisation of medicine can be guaranteed in these defining moments of a person's existence.

Naturally, this means that the patient must experience death with total responsibility and dignity. Although death may not be directly provoked, treatment must not be provided which does not have a significant effect on extending life or the improving the quality of life, but merely protracts the death throes uselessly with futile treatment. Everyone has the right to die with dignity and in peace without unnecessary distress, and all the treatment must be provide proportional to the needs of the patient.²⁵

We would consider disproportionate measures to be those which have little prospect of bringing about an improvement in the clinical condition of the patient, and the use of drugs and devices that are particularly costly or hard to come by, the absolute psychological rejection of treatment by the patient (in the case of serious mutilation, etc), extreme difficulties in the provision of care etc..

Disproportionate treatment can therefore be nothing short of *futile* treatment in the clinical sense. In this case, refusal may in fact be a moral duty.

5.2.4.2. *Emergencies*. In many centres in the Order there are Accident and Emergency units. Most of the ethical problems that arise there have to do with the state of the emergency in which the patients find themselves. In many cases, for example, their state of need makes it impossible to ask patients for their consent, with all the formalities this requires, and very often the relatives can only be given summary information. When there is strong opposition, the provisions of the Medical Code of Conduct and the laws of the land must be applied. Particular care must also be paid to the psychological state of the people accompanying a patient, who are often overwhelmed by emotion.

5.2.4.3. *Intensive care*. Intensive care units (cardiology, resuscitation, etc) demand a great deal of attention not only to the clinical conditions of the patient but also their psychological state. For these are facilities in which the patient knows perfectly well that they are in a critical situation, and could even die. This state of anxiety nearly always threatens to aggravate the patient's clinical

²⁴ Cf. Pius XII, *Allocution to the Società Italiana di Anestesiologia*, 24 February 1957; Sacred Congregation for the Doctrine of the Faith, *Declaration on Euthanasia*, 5 May 1980, no. III

²⁵ Cf. Congregation for the Doctrine of the Faith, *Declaration on Euthanasia*, *ibid.*

condition. Even the relatives can only play a minor part because of the frequent need to isolate them from direct contact with their loved one. In these cases, we must be sure to apply the humanising approach which will form an integral part of the treatment received during the period spent in intensive care.

5.2.4.4. Pain management. Physical pain and psychological suffering has always afflicted humanity which tries to treat it and very often becomes “resigned” to it. A poorly understood form of Christian ascetics (*dolorismo*) has misinterpreted the teachings of the Gospel, and considers pain and suffering to be unavoidable. For the truth is that if pain has to be addressed firmly and robustly, it must be fought against with all the means that contemporary medicine makes available to us. The healthcare facilities do not always, unfortunately, adequately apply pain therapy. In the Order's Centres, one major sign of care for the sick and humanisation must also be the fact that they provide adequate pain therapy.

5.2.4.5. Aesthetic medicine. In many social environments today, particularly in the West, concern for one's own image, together with the desire for an increasingly more sophisticated quality of life has led to a heightened demand for both medical and surgical treatments in the field of *aesthetic medicine*. This discipline belongs more to the *medicine of desire* rather than medicine catering for the *healthcare needs* in the strict sense of the term but, even though it is a branch of medicine and is practised in certain Centres in the Order, it must not be underestimated. The criteria used to conduct ethical discernment of requests for aesthetic treatment and practising aesthetic medicine referred to the purposes of treatment, an adequate proportion between the costs and the benefits, but above all the significance in terms of the overall wellness and well-being of the individual concerned.

5.2.5 *Research on humans*

5.2.5.1 Clinical trials. Research is one of the main ‘locomotives’ that have driven progress in medicine. Together with a number of chance discoveries, such as antibiotics or x-rays, research is responsible for all the achievements of science today. Research is no longer being carried out only behind laboratory doors or on animals, but directly on people. This experimental procedure is not an option which certain researchers wish to carry out, but has often become a vital necessity, particularly with regard to new drugs. After laboratory and animal experiments, every drug must be trialled for the first time on humans. Clearly, in this case the person is not being used as a guinea pig but simply to find the best possible way of applying the treatment being tested, which can subsequently be used for other people. This can only be done under certain strict conditions that have now been enshrined in international Charters and Declarations.²⁶ And since this research is carried out mainly in hospitals, our Centres should be aware of these conditions and apply them carefully.

The first condition is that every experiment must be carried out presuming that the effects will be beneficial. In other words, putting a previously nonexistent treatment or drug on the market should be done because it is better than another one for various reasons: more effective, less risky, cheaper, easy to administer, etc.

5.2.5.2. Informed consent. Obviously all experiments must be carried out with the consent of the person concerned. In order to ensure that this consent is valid, the person must be essentially free. This means that no influence should be brought to bear, even implicitly including ‘moral’ pressure, such as the influence of the physician speaking with authority, or the fear that otherwise the patient may not be properly treated.

This consent must also be ‘informed’, so that patients or guests know clearly that they are part of a clinical trial and are acquainted with the risks and benefits, the alternatives, the insurance

²⁶ Cf. Nuremberg Code, the Helsinki Declaration, Geneva Declaration, Good Clinical Practice, etc.. In addition to the criteria of the Magisterium see also *The Charter for Health Care Workers*, 75-82.

guarantees, etc. As a prior condition to ensuring that consent is truly informed, the patients and guests must be given exact details of their medical condition. One cannot indefinitely and routinely conceal the truth from them. They must be aware of their health status at all times. This does not mean that the truth cannot be revealed gradually or deferred in time, and shared with the relatives. And it certainly does not mean that they must be told at all costs when they have made it clear that they do not wish to know the truth. Neither should the truth be explained by going into distant and possible collateral effects. It is sufficient for the truth to be adequate.

5.2.5.3 Research on incapacitated persons and vulnerable groups. Everything that has been said above naturally refers to clinical trials carried out on individuals who are legally and ethically competent, in other words, able to fully understand what is being said and done to them, and to give their fully informed consent. But, but it cannot refer solely to them. This would exclude such patients as children, the mentally ill and people in a coma, or other incapacitated persons, who also need newly discovered treatments. This is why forms of ‘proxy’ should also be thought out to be entrusted to individuals whose specific bonds of affection with the patient or guest or because of an institutional function presumably enables them to be concerned at all times with their interests. Under these conditions, and having appraised the acceptability of the risk which the patient or guest is likely to run in terms of potential benefits, experimental trials of this kind may be lawfully conducted.

One specific problem arises with regard to experiments carried out on healthy individuals. It is difficult to find people willing to subject themselves to trials of this kind in exchange for nothing. Often, these individuals are prisoners, who are offered a reduction in their prison term. This practice is often justified as a sort of ‘tribute’ which they repay to society. At other times they are students who are paid for a service, or they may be ‘human guinea pigs’, recruited in developing countries for a paltry sum. It is unnecessary to say that the fundamental requirement in these cases is that the individuals concerned must freely accept to undergo the clinical trials and that in no case should their human dignity be impaired. In our Centres, we must always be very vigilant to ensure that any experimental trials carried out on healthy subjects is always done with their totally free consent and with adequate guarantees that no significant risks are involved.

5.2.5.4 Foetuses and embryos. With regard to prenatal experimentation there are two fundamental situations. Firstly, experiments carried out on ‘spare’ embryos produced in excess by *in vitro* fertilisation techniques. Very often this is done using the alibi of pseudo-humanitarian interests, claiming that it is much better ‘to use’ the embryo rather than destroying it or subjecting it to the risks of freezing. The second situation that may arise is experimentation carried out on pregnant women who have asked for an abortion. Here again, a foetus is ‘used’, claiming that it would at all events be destroyed. In reality, however useful such research might be for the benefit of other human beings, the actual result is to deliberately instrumentalise the human person, albeit for a noble cause, no longer viewed as an ‘end’ but simply a ‘means’.²⁷

The situation is quite different with experimental therapy, despite all the risks that may be involved, where it is possible to benefit the foetus on which a trial is being carried out. Obviously, the benefit must be potentially better than the situation without the trial or with the use of some other form of therapy.

5.2.5.5. Stem cell research and therapy. For quite some time now it has been possible to envisage the use of stem cells in the future treatment of certain tumours, neurodegenerative diseases, cardiac diseases etc. Stem cells are totipotent cells present in the embryo in the early stages of its existence (blastocysts), in the embryonic-foetal tissue of the umbilical cord and in certain adult tissues (marrow and adipose tissue, etc.). Apart from the scientific aspects of stem cell use and possible therapeutic applications, removing themselves from the embryo inevitably entails destroying the

²⁷ Cf. EV 63.

embryo against the possible benefits. As far as the use of cells from a miscarriage is concerned, even though this is lawful, one has to be sure that this does not constitute a means of legitimising abortion.

At all events, even for the use of adult cells, it is necessary to very carefully set off the risks against the possible benefits.

5.2.5.6. *Biobanks*. One newly emerging problem, at least in industrialised countries, but which could also affect developing countries as well, at least from the point of view of ensuring the supply of biological materials, has to do with biobanks. These are operating units or structures in which biological materials, such as stem cells, human tissue, surgical residues and DNA, are preserved and catalogued in special databases. These are intended to be used for study or research. And since the data is stored together with the biological data on the individual from whom the materials have been taken, a sensitive issue of privacy arises as well as the problem of making known the genetic information, especially when it presents pathological features.

5.2.5.7. *Ethics Committees*. There are two types of Ethics Committees: Research Committees and Clinical Ethics Committees. In some countries there is one single body to address both these spheres, while in others they are kept separate. To promote the various areas of clinical and pharmacological research, hospitals should set up research committees. These Committees are also a source of training and formation which encourage and foster opportunities for reflection, providing information, innovation and awareness-building in relation to care, science, teaching and administration.

The Ethics Committees, which should be set up or promoted in every Centre of the Order, are also there to defend the independence and autonomy of the patients and guests and to ensure that their rights are respected. They must be structured so that they adequately represent all the members of the Centre to which they belong, and above all they must be made up of ethically competent individuals.

Not every country has legislation on ethics and the composition of these Committees will often vary. In some countries there are 'national' Committees while others have hospital-based Committees. Some deal only with research, and others with clinical problems. Some are wholly independent, whereas others are linked to some other institution, etc.

Ethics Committees in all instances have three main functions.

The first has to do with *assessment and authorisation*. They are responsible for examining experimental medical and surgical trials. The Committees are therefore asked to give their considered opinion taking account of all the conditions permitting the experimentation (the rationale of the research, the proportion between risks and benefits, the protection of the patient, informed consent, etc.).

Secondly, they provide *consultation and make proposals*, when specifically requested by third parties (healthcare personnel, patients or guests, external entities, etc.) to offer opinions on issues of major ethical concern, or to shed light on situations of conflict where the healthcare workers' consciences are involved (ethical advice) and may lay down guidelines on important ethical behavioural matters.

Lastly, these Committees can have an *educational and cultural* function, and can be considered to be educational instruments to instil ethical sensitivity in the Brothers and the Co-workers/Employees in the Centres, promoting greater ethical competence on the part of personnel and health care institutions through various initiatives (conferences, publications, etc.).

To perform all these functions (except for those relating to trials) in some Centres, the Committees are flanked by *Bioethics Services* under various different names.

5.2.6 *Predictive medicine*

5.2.6.1 *Disclosure of the diagnosis.* Modern predictive medicine practised in many of our Centres raises bioethical problems that have never arisen before. The first of these is notifying the diagnosis. Who should be notified? The person concerned, their relatives, or both? The general ethical criterion regarding telling the truth to the patient or guest is that they are the first owner of this right, albeit not the only one, regardless of the seriousness of the illness. Indeed it is precisely when the prognosis is bad that the problem is particularly urgent.

The question of genetic diseases should not be an exception to this rule. However the particular feature of many of these diseases, where several members of the family may be affected by it, in clinical terms, raises the same question. Obviously it is not possible here to examine the problem in depth, and every individual situation must be carefully examined taking account of the 'rights' of all the persons affected, giving absolute priority to the patient or guest (who may never be robbed of something which relates so intimately to them) but also taking due account of the needs of their relatives, if the situation demands this.

Even more than in the case of other pathologies, when communicating the diagnosis of genetic disease account should be taken of the particular psychological and emotional state of the parents, and the most appropriate language has to be used which they can clearly understand without "terrorising" them, and while the truth is never to be concealed or manipulated, it has to be communicated "gently", respecting the decision taken by the couple but at the same time without saying anything to induce them to interrupt the pregnancy but, on the contrary, to help them to accept life even if it is affected by a serious pathological condition.

5.2.6.2 *The gene pool and the protection of privacy.* In the forthcoming stages of medical research, the possibility is opening up to have a complete knowledge of the gene pool of every individual, not only in terms of their physiological structure, but more important still, the possibility of appraising possible pathologies. While this is an indispensable condition for ensuring that they can be corrected some time in the future (through genetic engineering) the possibility also raises serious ethical problems.

The first has to do with the privacy and confidentiality of this data which, kept in 'gene banks'. In reality the problem is exactly the same as gaining access to clinical records or a computer. What it does, however, is to raise an old issue, namely the confidentiality of private information, in different terms. Perhaps what is most noticeable here is the depth and the 'intimacy' of a possible invasion of the most secret fibres of the human structure. But the criteria to be applied to other situations must also apply here.

Very closely linked to this problem is the matter of a kind of 'genetic identity card' of each individual and even devices for genetic self-diagnosis which are now beginning to appear on the market. What problems might such an instrument cause? How can it affect the psychological health of an individual, knowing that he or she is the bearer of various genetic illnesses which are not always clinically present but are potentially there? How will it influence problems relating to the choice of a life partner? Hitherto it has always been said that it is correct to prevent genetic diseases by a pre-matrimonial medical examination. This would be the last resort. But could it condition the choice of an individual in terms of love and affection? There is no doubt that the scenario is still a long way off, but we should be prepared for it in good time.

One final and more practical aspect, but no less important for that has to do with the professional implications and matters relating to insurance. It is not out of the question that at some future time an employer might be able to request the 'genetic identity card' (as one does today with a medical certificate) and as a result exclude any workers who are not suitable, either now or in the future. This would be a serious form of discrimination in the workplace; faced with this eventuality our

Centres' care philosophy must ensure that guarantees are in place to protect these workers, because this could otherwise constitute one of the new forms of poverty in the future.

5.2.7 *Social-ethical problems*

5.2.7.1 *Addictions*. In every age and in every community there have always been forms of physical or psychological dependency on various substances, often with a magical/religious connotation, but only today has the problem taken on ethical and social dimensions of such vast proportions. The main reasons are the widespread use of drugs today, particularly among the younger sections of the population, causing harm both to individuals and to society at large.

This is a very complex issue and the Hospitaller Order is required to examine it from various points of view, primarily in terms of the healthcare aspects raised by it: emergency services, clinical weaning-off procedures, and the medical treatment of complications.

Secondly, because of the psychological and educational measures to be adopted to help people overcome their psychological dependency. Although it is comparatively easy to overcome physical dependency, this does not apply to psychological dependency. For unless there is a powerful desire to fill the value vacuum which leads to drug addiction, an individual will never win the battle against substance abuse. This is also the reason why the Church is present throughout the world in a number of structures (homes, therapeutic communities) which have made it possible for former drug addicts to be completely rehabilitated and take their place in society again.

Lastly, let us not ignore the social dimension of this commitment by the Hospitaller Order, which is wholly consistent with its charism. For there is no doubt that addictions are among those 'new' forms of poverty of which we speak so much today, and to which the Order feels it is being powerfully called to respond.²⁸

None of these activities must be carried out in conflict with public services, of course, but they must complement them. This does not mean that we must necessarily endorse the legislative or social measures that are adopted if they are not considered to be in harmony with the charismatic mission of our Centres.

Among the cases of abuse of psychotropic substances today, close attention is being paid to the abuse of psychopharmaceuticals commonly used as sleeping pills or ansiolytics of which, particularly in the highly industrialised countries, indiscriminate use is often made in the form of self administration without a prior medical examination or instructions from a doctor.

Another important form of addiction is *alcoholism*, for the problem of alcoholism in some countries in the world is so widespread that it is vastly superior to that of drug use. Moreover, the social classes concerned are much more varied, and this is yet a further stimulus to the Order to effectively commit itself to this area.

In addition to these forms of dependency we must not forget tobacco addiction, above all because of the physical harm this causes (cancers, cardiovascular diseases etc) and new types of dependency (Internet, video games, compulsive shopping etc).

5.2.7.2 *AIDS sufferers*. The present spread of this disease and its social stigma require our Order to find a viable response to it which may be summarised in terms of various initiatives.

The first must be cultural, to avoid allowing an mental attitude and our resultant external behaviour to discriminate against these people. This becomes very necessary in all healthcare situations in

²⁸Cfr. P. MARCHESI, *The Hospitality of the Brothers of St John of God towards 2000*, Rome 1986, Appendix III

which HIV positive or full-blown AIDS victims are in a general hospital for various reasons (first aid, needing surgery, etc.), sharing their in-patient status with other patients and visitors.

This attitude of welcome and outreach must also be more appropriately expressed in a spirit of specifically implementing a charismatic dimension, in special programmes to accommodate the patients or to accompany those who are in the terminal phase of the disease. The Order should promote these structures, imbued with that Christian spirit which it has always shown when caring for the most deprived and marginalised. Indeed from the point of view of our historical legacy, let us never forget that it was precisely to individuals affected by infectious diseases that many of our Brothers stood out so heroically in past ages.

In addition to looking after these patients, the Order must also contribute to preventing the disease, mainly by educating people in sound values. If such strategies prove ineffective or inadequate, any further harm may be reduced by making people aware that since all these measures in themselves are fallible, they will never provide an absolute guarantee of prevention from infection.

Furthermore, as far as possible the Order should cooperate in research carried out by other healthcare organisations or institutions to identify new remedies and therapies, or preventive remedies so that this disease can be finally beaten.

Particular social and ethical problems arise in developing countries. Above all in relation to the antiretroviral drugs, in terms both of their cost and the resultant difficulties of acquiring them, and also the existence of certain political problems which hamper their procurement. Another problem is breastfeeding. Even though this is not really suitable for HIV-infected mothers in developing countries, it is at all events preferable because, given the high child mortality rates it does have a protective effect on newborn baby's health, which outweighs the risk of infection.

Lastly, we must be particularly careful to ensure that our genuinely deep human understanding and acceptance of AIDS sufferers and our rejection of all forms of marginalisation and of any notion that AIDS is some kind of 'punishment from God' does not lead to sanctioning as lawful the behaviour that gives rise to it.

5.2.7.3. Other infectious diseases. In some parts of the world there are various infectious diseases such as malaria, tuberculosis and a number of new viral diseases (SARS, bird flu, haemorrhagic fever from the Ebola virus etc) which cause numerous deaths. In countries where these pathologies are widespread, and in which the Order is also present, medical care and human attention for the patients affected by these diseases must be an absolute priority in our care work.

5.2.7.4. Orphan drugs and rare diseases. Rare diseases, most of which are genetic in character, are defined as such because of the very few numbers of sufferers (generally fewer than one case in 2000 inhabitants). Even though each one of these is rare, they become numerous when taken as a whole (over 7000) and many of them are very debilitating. But it is precisely because of their rarity that they are very often difficult to study, in addition to the fact that they are of little "economic interest" to the drugs industry which is reluctant to invest in studying and treating them. To these conditions is related the problem of the "orphan drugs" which are only effective for treating or improving the symptoms of the disease, which are not manufactured or produced in an adequate manner because of the lack of a sufficient return to the pharmaceutical industries. It is mostly patients' associations and voluntary organisations, which are also concerned with raising funds for research and treatment, that are engaged in sensitising society to rare diseases and orphan drugs.

5.2.7.5. People with physical, mental and sensorial disabilities. Even though contemporary society seems to have rediscovered attention to people with disabilities today, while generally accepting them as being 'different', by special measures such as removing 'architectural barriers', in terms of culture and people's mindsets there still remains a certain rejection of them. This extends to the promotion of prenatal eugenics, pushed to the point of destroying embryos affected by any anomaly, and demanding euthanasia to dispose of malformed new born babies or disabled adults.

But there would be no point in pointing the finger of blame for all this unless, at the same time, we work to ensure that welcome and love is shown to all the disadvantaged members of any society wishing to be called civilised. A society really made to the measure of mankind cannot be directed to the 'strong' but must be directed towards the 'weak'. In addition to taking specific measures to support the disabled, the Order should have this function of bearing witness.

In compliance with the principles of *participation, inclusion and personalisation*, the Order is being called upon, in particular, to encourage people with disabilities to lead a more autonomous life by encouraging their incorporation and participation in social life and in the world of work. For this reason it is necessary to encourage de-institutionalisation, by converting large-scale structures into smaller and more homely facilities, in which adequate protection can be provided in every respect.

One particularly sensitive problem refers to the exercise of sexuality an essential condition for this is that it must be freely chosen. There are various levels of restriction on the freedom of choice in this regard while sexual stimuli are simultaneously present. While any action intended to mutilate a person's functions is disrespectful of human dignity (in this particular case, a person's reproductive function) on the other hand, a person who is mentally impaired is not only unable to freely exercise that faculty, but its use, while its biological potential is unaffected, can lead to pregnancy. This is precisely why, when seeking to guarantee the maximum respect due to every human being's full bodily identity we must responsibly prevent a person with mental disabilities from causing self harm and damage to others precisely because of their particular existential conditions.²⁹

5.2.7.6. *The mentally ill.* Because of the personal experience of our Founder, the mentally ill have always been particularly cherished by our Order. We have therefore built up a great deal of experience and skills with them, and indeed have often been in the vanguard in heralding in new ideas and solutions which are now being used by the public health authorities themselves. Yet, apart from a number of specific care problems relating to the legislation in various countries, they also raise specific ethical problems.

The first is what might be considered the common denominator shared with all the others, namely, their capacity to give their consent. Overcoming the medical paternalism of the past and the present appreciation of the autonomy of the patient also applies to the mentally ill. Indeed, it applies to them even more radically, because of their limitations when having to take autonomous decisions. There may therefore be a temptation to return to the old form of paternalism in their case, even though this may well be for charitable reasons. But this must not be done, and should only be limited to cases in which the state of need or the lack of any other relatives or Bioethics Committees, etc., means there are no alternatives and no one else with whom to share decisions. In all cases, the patient must be part of any decisions taken in so far as their faculties permit, or we must involve persons whose bonds or role suggests that they would always work in the best interests of the patient.

This is evident in the case of sedation with psycho-drugs, electro-shock treatment, physical restraint measures and the deprivation of freedom. But when this is done, it is sufficient to have a general and often implicit consent expressed by those authorised to issue it whenever it becomes indispensable to admit the patient.

At all events, and apart from these specific problems, the Order's psychiatric or social facilities must always be imbued with profound humanity in the treatment shown to the mentally ill. This is part of the perennial charismatic practice of that particular sensitivity that St John of God showed to

²⁹ John Paul II addressed the sensitive issue of the sexuality of people with disabilities in his message to the delegates to the International Symposium promoted by the Congregation for the Doctrine of the Faith on "The Dignity and Rights of the Person with Mental Disabilities" (8 January 2004).

these persons, as well as being a renewed prophesy in an environment which is constantly in need of humanisation. This should not be viewed merely in terms of guaranteeing sick people adequate living space, a satisfactorily hygienic environment, food of good quality, freedom of movement and the possibility of maintaining links of affection with their family, etc., but must also extend in positive terms to the person's 'self-fulfilment'. In order to achieve this, we must appeal to the potential of the individual, to all his or her resources, including spiritual resources. This is a process which should lead us to appreciate a personality which, despite impairment, always allows the face of man to shine through.

In this perspective the importance of de-institutionalising these patients must always be borne clearly in mind. With rare exceptions, they should always be admitted to facilities in which they are not "confined", but live in sheltered communities where they can also have the opportunity to find employment wherever possible. With regard to the exercise of sexuality on the part of the mentally ill references made to the comments in the previous section dealing with persons with mental disabilities

5.2.7.7 Older people. The older generation is continually growing in contemporary society, not only increasing the diseases and illnesses from which they suffer, with an increased commitment that this entails in terms of healthcare, but also creating specific social and welfare problems as a result. The real difficulties faced by certain families in looking after old people within the family, or the selfish rejection of them by others, often make it necessary for old people to retire in a rest home. There are now many such facilities managed by the Order in different parts of the world.

Naturally, there are many reasons why an old person ends up in a home. Even though we have no right to judge the families that have chosen to put their elderly relatives in a home, the Order must as far as possible encourage the bonds of affection between them and their family, also by helping to remove any possible obstacles to this.

We should not view the stay of an old person in a House managed by the Order as a solution to a housing problem alone, but it must be fully imbued with its charismatic meaning and sense. This means that we must appreciate the 'third age' which must not be masked by the illusion of some eternal youth, but experienced as a specific and different age in life, with all its riches and problems, the same as every other stage in life. At the same time, however, we have to avoid the tendency which is known today as "ageism", considering old people useless, unproductive and therefore not particularly important for the development, especially the economic development, of society.

In old age, people suffer from the experience of loss (of physical strength, social role, affection, work, a home, etc.) which they must internalise and compensate for by other forms of enrichment (experience, memories, the good they have done in the past, etc.). Moreover, particularly when one considers the many forms of neglect and maltreatment to which old people are subjected, our Centres must stand out as shining examples of respect for the dignity of the elderly and the humanisation of their care.

Lastly, looking at it from the point of view of the faith, this time can also be seen as a long vigil in preparation to encounter eternity.

5.2.7.8. Abuse of children, adolescents and the vulnerable. One of the problems that has emerged in recent years (because of a greater understanding of the problem or because it has really increased) is the abuse of children, adolescents and the incapacitated, and violence in general. This may take the form of physical, psychological and sexual abuse. As far as the Order's facilities are concerned, one particular form of abuse is of an institutional nature. In hospitals, all these kinds of abuse can occur together with specific kinds of institutional abuse, such as:

- failure to respect privacy;

- inappropriate isolation;
- intimidation;
- inappropriate dietary treatments;
- refusing food;
- indifference when nursing them.
- failure to respond to requests for help.

It is unnecessary to stress the seriousness of any kind of abuse, by whomsoever it is committed, even more so the particular seriousness of abuse when it occurs in an institution, both because the institution should guarantee children and adolescents a welcome, care and protection, and because the abuses is committed in institutions belonging to the Order. When any cases are discovered, in line with what the Church is doing, all the necessary disciplinary measures must be taken against the perpetrator of abuse, but above all the victim of abuse must be given care and attention. For while abusers must be treated with appropriate severity, it must not be forgotten that it is the abused person who is always at the heart of the problem, and needs to process and be properly healed of the traumatic experience.

It might be appropriate, as some countries already doing, to draft special protocols for the prevention and treatment of any cases of abuse.³⁰

5.2.7.9 Immigrants, the homeless and other marginalised people. The presence of *immigrants, refugees and political asylum-seekers* is a sharply increasing phenomenon in every Western country. Although the problems this raises are mainly social (cultural and religious integration, employment problems, etc.) it is also an area in which the charism of hospitality may find specific expression. Responses to this problem vary enormously, depending upon the creativity of those who heed the promptings of the Spirit, and they may also be encouraged by the specific needs of each individual country or social situation. Naturally, in addition to the fact of making migrants welcome, there are also healthcare problems for people who often are unable to use any other form of public assistance or care. The Order must also work to solve these needs both by setting up special structures where possible, and by finding appropriate solutions to these problems within its own Centres.

A similar situation arises with another group of persons classified variously as *homeless, vagrants, squatters*, who share the common feature of suffering from such radical poverty that they cannot possess any form of stable abode because they are forced to live in the streets, in doorways,. Perhaps the scenario of this suffering humanity, despite the passage of so many centuries, is very similar to what St John of God or St John Grande was confronted with. Every measure to care for these people (material, accommodation, healthcare, etc.) falls in the line of absolute charismatic continuity for this very reason.

In addition to these situations it is quite likely that in future years the Order may well be required to make a prompt response to other situations which at the present time are still rare or less noticeable. For example, the women who are victims of violence, children who have suffered abuse, individuals who have tried to commit suicide, the loneliness of widowhood, psychological eating problems (anorexia and bulimia) etc. Adequate attention to the needs of suffering mankind must necessarily also take account of these 'new forms of suffering' which may arise as time passes, and which the Order must always be ready to address with creativity and love.

5.3 The text is not been revised because not deemed to be within the remit of the Bioethics Commission

³⁰ Cf. The Order's document on "Care and Protection in Hospitality: guidelines for care policies and the protection of children, vulnerable adults and older people in the Order's Apostolic Centres and Services. 2010

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- 5.2.1.6. Assisted reproduction
- 5.2.1.7. Female genital mutilation
- 5.2.1.8 Gender reassignment
- 5.2.2. Organ donations
 - 5.2.2.1. Organ transplants
 - 5.2.2.2. Ascertaining death
- 5.2.3. Chronic sick those at an advanced stage of illness
 - 5.2.3.1. Euthanasia
 - 5.2.3.2. Living wills
 - 5.2.3.3. Vegetative state
 - 5.2.3.4. Palliative care
 - 5.2.3.5. Palliative sedation
 - 5.2.3.6. Terminal foetus
- 5.2.4. Ethics of treatment
 - 5.2.4.1. The proportionality of treatment
 - 5.2.4.2. Emergencies
 - 5.2.4.3. Intensive care
 - 5.2.4.4. Pain therapy
 - 5.2.4.5. Aesthetic medicine
- 5.2.5. Research on human beings
 - 5.2.5.1. Clinical trials
 - 5.2.5.2. Informed consent
 - 5.2.5.3. Research on incapacitated individuals and vulnerable groups
 - 5.2.5.4. Foetuses and embryos
 - 5.2.5.5. Stem cell research and treatment
 - 5.2.5.6. Biobanks
 - 5.2.5.7. Ethics Committees
- 5.2.6. Predictive medicine
 - 5.2.6.1. Announcing the diagnosis
 - 5.2.6.2. The gene pool and the protection of privacy
- 5.2.7. Ethical-social problems
 - 5.2.7.1. Addictions
 - 5.2.7.2. AIDS sufferers
 - 5.2.7.3. Other infectious diseases
 - 5.2.7.4. Orphan drugs and rare diseases
 - 5.2.7.5. Persons with physical, psychological and sensorial disabilities
 - 5.2.7.6. The mentally ill
 - 5.2.7.7. The elderly
 - 5.2.7.8. Abuse of children, adolescents and vulnerable people
 - 5.2.7.9. Immigrants, the homeless and other forms of marginalisation