

Hospitaller Order of St John of God

ETHICAL REFLECTION ON THE END OF LIFE



European Board of Bioethics

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PRESENTATION

In view of the debate that has recently been reopened in several European countries around the issue of decriminalising euthanasia, the European Board of Bioethics of the Order of Saint John of God felt it was an appropriate time to provide an opportunity for reflection, that has culminated in this document.

Its purpose is to reaffirm our pro-life position, to understand the varying positions and current legislation in different countries in Europe, and to remind ourselves of the principles and guidelines defined and promoted by the Order of St John of God in different ways.

This document has therefore drawn on the laws and the main changes and debates taking place in our European societies. It sets out the position of the Church and the Order, and ends with a number of operational proposals on how to deal with the complex issue of the end of life.

It was decided to have one member of the Board of Bioethics as the principal author, and Dr Maria Teresa Iannone was appointed to draft the paper and lead the project. The other members of the European Board of Bioethics acted as co-authors.

We would like this document to be read and disseminated to be used as input to a more in-depth study of these issues that currently form part of our social debates and concern areas of work of relevance to many of the Order's centres. We hope that it will be of interest to you and thank you for your attention to these topical issues of concern.

European Board of Bioethics

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Foreword

We are increasingly hearing it said, often through public opinion polls, that it seems better to die than to live without dignity, and that we therefore have to fight a battle of civilisation that has always been ignored in the past by a bigoted society dominated by an obscurantist Church.

We must therefore ask ourselves what 'dignity' means according to public opinion, to ordinary people who are not always aware of the complexity of some of the arguments, and what is the yardstick for deciding how long our life has dignity: is it a matter of choice or will? Is the legal sanctioning of euthanasia really the recognition of a right? and is this a right which a civilised state must recognise? And has our medical world and the health care organisation representing it really done everything possible to ensure that no suffering individual is left alone with their pain and their "certainties"?

Looking more closely, we cannot fail to see that public opinion is being fed with semantically false messages; we cannot be certain that all those who address the subject have the tools they need to express themselves using the words we frequently read. And we may say that it is not so much "the Church", but rather a certain kind of scientific Medicine seeking to defend itself that prefers a reassuring solution to the difficult relations that exist in our hospitals today.

Lastly, are we convinced that these claims to the right of self-determination are what people currently experiencing sickness are really advancing? We only have to take a tour around the hospitals, Catholic and otherwise – at least in some of the European countries that have not yet taken the decision to accept euthanasia – to realise that the demands are very different from what are to be found on Facebook, and that we should be concentrating on rebuilding the doctor-patient relationship that, over time, has often led the two main parties responsible for protecting human life and health to become moral strangers.

Modern technological medicine is being asked to do increasingly more, often losing sight of the disproportionately small benefits. Our society goes out of its way today to dispel the thought that death is also a moment in life; medical progress, with its continuous output of scientific knowledge, unlimited technological resources, and its modern organisation, has brought about radical changes in the natural evolution of many diseases, to the point of filling life and death with biological and technical content, while professional responsibilities have

been increasingly relegating the human, spiritual, moral and social aspects into the background and overturning philosophical, political and, consequently legal, approaches.

To help everyone acquire the deep moral conviction that the freedom and autonomy/self-determination of every individual is not a matter that is based on second-hand information and pseudo-journalistic research, to which we respond with a rush of emotion in which the suffering of borderline cases can easily involve us, we have to continue the reflection on it, starting with the ontological nature of the complexity of the human being that cannot be reductively trivialised, often causing people to fail to see their dignity being properly appreciated.

Yet we have to recognise dignity as taking precedence over life itself if we expect it to truly represent who we are, and be accepted as a pre-legal requisite that the law can only recognise, but not determine. To think otherwise would make everything in our lives becomes measurable, like a biological requirement in the hands of Man, which would include the reason for our very existence in the world. A society that merely recognises what we desire, but does not accept us wholly as we are, is a society that fails to attain its most important purpose: to respect the citizens who comprise it. Human progress cannot be considered to be developing if Man is not allowed to live until our final moment, and if civil society is not committed to seeking every possible means to ensure that this can take place while respecting Man, our needs, our sufferings, and our fears. This alone can ensure that human dignity can become the foundation underlying all the social, institutional and cultural battles that are necessary to ensure Man's freedom, that cannot be construed to mean the ability to do all and anything, but rather to spontaneously seek what is good by allowing every community to protect important values.

Quite clearly, the meaning, as well as the quality, of life of those who are passing through their final moments must not be a problem that they are expected to solve in the loneliness of their own consciences, but its something that should concern the whole community, in a debate involving very challenging economic, social and legal policy decisions. Yet we must not underestimate the heavy responsibility falling to those who are responsible for policies to protect the whole human person, rather than offering hypocritical solutions which, in an attempt to demonstrate that they have complied with an alleged right to die, produce an equally serious result as imposing aggressive treatment: therapeutic, social, moral and human abandonment.

The situation in Europe

From a legal point of view, the European Union has no competence in the matter of legislation governing the end of human life: individual States are free to decide on end-of-life matters. The laws enacted over the last twenty years differ widely, but they have recently become more consistent. To understand the initial differences, we have to examine not only the various ideological and political positions of the European countries that are sometimes very wide apart, but also their cultural and ethnic identities in terms of different social relations and family structures, even within one and the same sovereign state.

For the European Union States, the only common benchmark is the Convention on Human Rights and Biomedicine signed in Oviedo on 4 April 1997, which we may consider to be the first biomedical legal instrument promoted by the Council of Europe.

Art. 5 provides that: *“An intervention in the health field may only be carried out after the person concerned has given free and informed consent to it. This person shall beforehand be given appropriate information as to the purpose and nature of the intervention as well as on its consequences and risks. The person concerned may freely withdraw consent at any time.”*

And Article 9 provides that: *The previously expressed wishes relating to a medical intervention by a patient who is not, at the time of the intervention, in a state to express his or her wishes shall be taken into account.*

This is a matter that certainly demands a painstaking analysis, and the necessary starting point must be to consider solutions that have never been dictated by need but rather as the result of a wider reflection. And the assumptions underlying different countries' positions or their current discussions on euthanasia – which literally means *good death* – to guarantee the right to choose whether or not to use it, are based on the idea that if there exists a right to life, a right to death perhaps can and *must* also exist.

In the past twenty years, Europe has been engaged on a very heated debate on end-of-life issues, leading both to some highly nuanced solutions and other more radical ones, with some countries recognising euthanasia and others still prohibiting it considering it to be murder. Different countries' stances have varied, and we should therefore examine the language used to define the different practices relating to the direct management of the final stages of life:

- *euthanasia* in the strict sense of the term, as *active euthanasia*, is seeking death to end a person's sufferings, with death being brought about caused by administering lethal drugs;

- *passive euthanasia* is, improperly called, when death is the result of interrupting or failing to administer the proportional and necessary medical treatment for ensuring survival;
- *assisted suicide*, on the other hand, is when a health worker "advises" the patient about the drugs to be taken, under conditions in which the patient materially plays an active part in administering them;
- the *Advance Care Directive* - also called a *living will* - lays down instructions which an adult, being of sound mind and will, freely directs any future physician how to treat them when they are no longer able to understand and express their will, including the administration of life-saving treatments. There are various ways of doing this, either through a notary public or by means of a simple written statement delivered personally to a local public servant, with or without witnesses but always ensuring that it is possible to trace the document back to the signatory. They can be revoked or amended.

The action performed is therefore:

- . *voluntary* when it is performed according to the explicit request of anyone sound of mind and able to understand and express their will, or under a living will;
- . *involuntary* if it is performed against the patient's will.

The position of the Church and the Order

Introduction

Today, in our post-modern age, opinions regarding the end of life are changing, as we have already seen, and in Europe, when considering the acceptance of the end of life, the concept of the quality of life is increasingly becoming seen as the sole criterion for personal choices expressed in solitude, leading to a gradual and also cultural, loss of the sacred character of life. Today's Europe is certainly in difficulties from which it is not difficult to extrapolate the idea that we can no longer refer to human dignity as being able to be taken for granted today when we look at the modern European covenant, and Europe's relations with the rest of the world.

And so what must be our response to the destructive power of suffering? Are we still in the true and the right, in the good and the beautiful, now that we have attributed an axiological value to "difference", distorting it from being an inherent condition of existence to make it a

"value" that is a slave only to economic power relations, denying human beings their socio-ontological nature?

How can the Order respond to such fragility?

The Order's Charter of Hospitality

The initial paragraphs in chapters 4 and 5 of the Order's Charter of Hospitality dealing with the ethical views of the Order's mission, offer us a number of ideas to identify fundamental insights on which to base an end-of-life reflection.

4.1.1. Respect for the human person.

The dignity of every human being in God's eyes is the basis of their dignity in men's eyes, and in their own.

...

Our duty of self-esteem and self-love comes from the dignity of the human being in the eyes of God.

4.1.3. Welcoming the sick and the needy. 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.

4.2.1. Life as a fundamental right of the person. 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.

4.2.4. 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.

5.1.2.3. Autonomy. (...) 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 must 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.

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.

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.

5.2.3. *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. 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. 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 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. However, many people are of the opinion that the purely medical ways in which this is performed could be equated with a therapeutic measure.

5.2.3.4. 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.

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 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 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.

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 provided proportional to the needs of the patient.

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.

The New Charter for Health Care Workers by the Pontifical Council of the Pastoral Care of Healthcare Workers

Dying with dignity

Art. 149

In the terminal stage, the dignity of the person is elucidated in his right to die with as much serenity as possible, and with the human and Christian dignity that is owed to him.

Preserving the dignity of dying means respecting the sick person in the final stage of his life, refusing both to hasten death (euthanasia) and to prolong it through therapeutic obstinacy. Contemporary man has come to be explicitly aware of this right to be protected, at the moment of death, from “a technological attitude that threatens to become an abuse”. Indeed, modern medicine has means at its disposal that are capable of artificially postponing death without the patient receiving any real benefit.

Art. 150

Aware that he “is not the lord of life, ... neither is he the conqueror of death,” a health care worker must choose appropriately in evaluating the means. Here he applies the principle—discussed earlier—of the *proportionality of treatment*, which can be defined as follows: “When

inevitable death is imminent in spite of the means used, it is permitted in conscience to take the decision to refuse forms of treatment that would only secure a precarious and burdensome prolongation of life, so long as the normal care due to the sick person in similar cases is not interrupted." Therefore, the physician has no reason to torment himself as though he had not provided any assistance.

Forgoing these treatments, which would only procure a tenuous and painful prolongation of life, can also indicate respect for the dying person's will, expressed in statements or advance directives concerning treatment, while excluding any act of euthanasia.

The patient may express in advance his will concerning the treatments to which he would or would not wish to be subjected in a case where, over the course of his sickness or because of unexpected trauma, he is no longer capable of expressing his own consent or disagreement. "The decisions should be made by the patient if he is competent and able or, if not, by those legally entitled to act for the patient whose reasonable will and legitimate interests must always be respected."

The physician is not a mere executor, however; he keeps the right and the duty not to carry out wishes that conflict with his own conscience.

The Catechism of the Catholic Church

2258 "*Human life is sacred* because from its beginning it involves the creative action of God and it remains for ever in a special relationship with the Creator, who is its sole end. God alone is the Lord of life from its beginning until its end: no one can under any circumstance claim for himself the right directly to destroy an innocent human being."

Euthanasia - 2276 Those whose lives are diminished or weakened deserve special respect. Sick or handicapped persons should be helped to lead lives as normal as possible.

2277 Whatever its motives and means, direct euthanasia consists in putting an end to the lives of handicapped, sick, or dying persons. It is morally unacceptable.

Thus, an act or omission which, of itself or by intention, causes death in order to eliminate suffering constitutes a murder gravely contrary to the dignity of the human person and to the respect due to the living God, his Creator. The error of judgment into which one can fall in

good faith does not change the nature of this murderous act, which must always be forbidden and excluded.

2278 Discontinuing medical procedures that are burdensome, dangerous, extraordinary, or disproportionate to the expected outcome can be legitimate; it is the refusal of "over-zealous" treatment. Here one does not will to cause death; one's inability to impede it is merely accepted. The decisions should be made by the patient if he is competent and able or, if not, by those legally entitled to act for the patient, whose reasonable will and legitimate interests must always be respected.

2279 Even if death is thought imminent, the ordinary care owed to a sick person cannot be legitimately interrupted. The use of painkillers to alleviate the sufferings of the dying, even at the risk of shortening their days, can be morally in conformity with human dignity if death is not willed as either an end or a means, but only foreseen and tolerated as inevitable Palliative care is a special form of disinterested charity. As such it should be encouraged.

Letter of the Congregation for the Doctrine of the Faith "Samaritanus bonus"

The Congregation for the Doctrine of the Faith has also expressed its opinion on euthanasia and assisted suicide, and in its Letter "Samaritanus bonus", the Congregation strongly condemns all forms of euthanasia and assisted suicide. "The Church is convinced of the necessity to reaffirm as definitive teaching that euthanasia is a crime against human life because, in this act, one chooses directly to cause the death of another innocent human being (...) Euthanasia is an intrinsically evil act, in every situation or circumstance."

The document on the end of life is in its final stages in response to the Pope's requests on these issues and is in line with his constant teaching in defence of the weak and precarious situations that exist in our society. The Congregation for the Doctrine of the Faith has issued this document to give operational guidance to help people live the final moment of their lives in a humane and Christian manner. Pope Francis has recalled that it is necessary to create a real human platform of relationships around the sick which, while fostering medical care also bring hope, especially in those borderline situations in which physical evil is accompanied by emotional distress and spiritual anguish. The relational - and not merely clinical - approach to the sick, viewed in their uniqueness and totality, requires us never to abandon anyone in the

presence of incurable evils. Human life, on account of its eternal destination, preserves its full value and dignity in all conditions, even precariousness and fragility, and as such is always worthy of the highest consideration.

This document affirms that “care for life is therefore the first responsibility that guides the physician in the encounter with the sick. Since its anthropological and moral horizon is broader, this responsibility exists not only when the restoration to health is a realistic outcome, but even when a cure is unlikely or impossible. Medical and nursing care necessarily attends to the body’s physiological functions, as well as to the psychological and spiritual well-being of the patient who should never be forsaken. Every individual who cares for the sick (physician, nurse, relative, volunteer, pastor) has the moral responsibility to apprehend the fundamental and inalienable good that is the human person. They should adhere to the highest standards of self-respect and respect for others by embracing, safeguarding and promoting human life until natural death.

We must defeat the culture of death which tends to dominate today, because “Among the obstacles that diminish our sense of the profound intrinsic value of every human life, the first lies in the notion of “dignified death” as measured by the standard of the “quality of life,” which a utilitarian anthropological perspective sees in terms “primarily related to economic means, to ‘well-being,’ to the beauty and enjoyment of physical life, forgetting the other, more profound, interpersonal, spiritual and religious dimensions of existence”. In this perspective, life is viewed as worthwhile only if it has, in the judgment of the individual or of third parties, an acceptable degree of quality as measured by the possession or lack of particular psychological or physical functions, or sometimes simply by the presence of psychological discomfort. According to this view, a life whose quality seems poor does not deserve to continue. Human life is thus no longer recognized as a value in itself.

Operational proposals

For the Order of St John of God, caring for the sick is not a mission that merely supplements or replaces care by the public authorities. It is a response to a specific command of Jesus: "Heal the sick" (Mt 10:7), which obliges it to maintain its commitment with and among the sick, as an original way of expressing God's love for humanity.

The guiding value of Hospitality in the operational decisions taken by the Order must be to ensure that we do what is necessary to cater for needs arising outside the Order, seeking understanding and respect in order to formulate truly welcoming care plans. Hospitality must express intelligence in order to propose concrete benchmark models to ensure that the Order's values form the basis for ensuring continuity between the past, the present and the future; Bioethics can be an aid to designing solutions because it is essentially a dialogue to stimulate reflection, nourished by interdisciplinarity.

We cannot remain indifferent to the social distress of the people; this is why, in the face of pressures that seem to want to lead us to drift into utilitarianism or away from our vision of the sacred nature of life, it is also necessary to launch projects that will bring to life our analysis of the values that underlie the Order's work, to enable us to combine the wealth of the Charism of Hospitality with the complexity of real life.

Palliative care education as a response

There is no doubt that the palliative care system needs to be strengthened in all countries. This is because euthanasia and assisted suicide are now driven by a powerful economic ideology. Of course, there is no freedom of choice for the sick if the only chance they are offered to fight pain and suffering is to end their lives: the rights of the sick are only guaranteed if there is also the possibility to choose ways of looking after them, such as palliative care, which is widely demonstrated by the almost total lack of euthanasia requests in the centres that provide it. This at least is the case so far, and until the process of changing mindsets is complete.

There is no investment in palliative care, whereas measures should be improved to guarantee everyone access to it, because radical changes in modern medical practice require decisions that translate into concrete applications. Otherwise the much-vaunted humanisation of care, even at the public level nowadays, runs the risk of remaining wishful thinking..

Having a good palliative care system is the first step towards giving voice to the subjective dimension of suffering in sickness, and making treatment not only an ethical duty but the example of good clinical practice in step with the times, dealing with patients who, when no longer able to think of a recovery are still in need of care, that supports their families, and that trains health professionals.

Since the alleged right to die is being advocated on all sides, we have to address these claims, but certainly not by pandering to them and neither by simply trying to block them. Our duty is to reflect seriously on the need to create an ethical environment where we can create a pathway to caring for people in their suffering. The operational instruments and tools needed to lay down this pathway must be identified and agreed by everyone operating in the health care field, including management, to ensure that economics and ethics can coexist in clinical service.

Health professionals must devote themselves to the sick with a humanising approach to enable them to live until death with full dignity; this is the prerequisite with which to think about palliative care and this is the starting point for working out future ways of coping with end-of-life difficulties: offering real answers. Only in this way, not by simplifying such a complex phenomenon as suffering, that we can accompany people throughout their sickness with respect for life which, even in the most distressing situations, manifests its sacred character and its inviolability.

The rediscovery of relationships

The risks linked to a social change of mentalities can have operational consequences and give rise to difficulties unless we take account of the factors that have to do with information and the doctor-patient relationship.

Moving beyond the Hippocratic model has led to the recognition of a modern patient who is aware and participative in his or her health choices; information is a right that allows the patient to express their endorsement of the therapeutic project by expressing consent. But this is good and true if the right balance is maintained between the dimension of the professional choice made in science and conscience by the healthcare professional and the patient's conscious acceptance. For we must be very careful to ensure that an abstract conceptual statement of self-determination does not undermine the fragility of the person in care, which can only emerge in an interpersonal care relationship.

Working properly on relationships is also the only way to overcome aspects that might mortify the role of the doctor by depriving them of the right to choose autonomously, according to science and conscience, shared with the patient by joint agreement, thereby encouraging a bogus relationship of care that risks becoming a kind of 'notarial' process of

recording the patient's will by completely subordinating it to the patient's legal decision in the name of a principle of self-determination which, rather giving greater freedom to the patient, seems to indicate a utilitarian vision of life, thereby making the relationship of care and healing a kind of contractual relationship, forgetting or ignoring the fact that the ability to decide is one of several complex variables that are not only cognitive.

As human beings, we have an intimate need to share and talk. Truth, culture, logic and facts survive and are handed down thanks to this need to foster changes in attitudes and behaviours both on a personal and a collective level.

This makes it essential to provide both initial and continuing formation for doctors and other health professionals dealing particularly with relationships and communications with the patient, as well as with the family members and with any proxies/guardians, emphasising the extreme importance of the relationship of care and trust through concrete actions, including organisational actions.

Experiencing relationships during training offers a real opportunity to come to an agreement, to tune in to the other person – that is to experience contact. For the fact remains that in our day-to-day healthcare work we must never ignore the lack of communications which forms the basis of relations in the relationship of care, while what is necessary is to convert a disease-based approach to a person-based approach.

We must work to ensure that *consent* is defined in a broader sense than the one now reductively framed in legal documents, to require the carers to offer prior complete and effective information regarding its complexity and possible outcomes that may result. And so it must not be defined in advance, but be built up only thanks to the intervention of the doctor, who is not a technician required to do the patient's will but the person who has the skills to make the decisions and then to help the patient to understand and consent. It is the patient who must be the focus of the care and treatment and the final arbiter of the decisions, but based on the choices that are clearly presented to the patient, with the support of those who will then have to act with and on them.

Once the need for information is recognised, including the real impact that the disease will have on the quality of life of the patients and their family and the real care welfare opportunities available, it is obvious that the information must not only be supplied by the doctor, even though the doctor is responsible for recording the patient's consent, but also by

the other people who are directly responsible for quality of life, such as nurses, psychologists, social workers, and clinical ethics consultants. It is only such broadly-based information that can enable people to give truly informed consent – to refuse or revoke it.

In this way, ACDs or living wills can also recover their relational character, by dropping their reductive role of the advance delivery of sterile indications of will detached over time, to become the necessary vehicle for patients to continue their relationship of care even when their ability to prove their presence no longer exists.

The appropriateness of ethical advice

One of the reasons for Bioethics is the very complexity of modern Medicine, which is having to take on new responsibilities for a society that is increasingly more sensitive to protecting autonomy, but which always poses new questions about matters relating to life; the intrinsic need for ethics in the medical practice reveals its problematic nature precisely whenever a clinical decision is taken, namely, when faced with a supremely human act which, while the expression of free will, requires careful prior examination of all the cognitive elements to justify the action itself.

Precisely because it is not easy to carefully appraise all the values in play that respect both the professionalism and the conscience of the medical practitioner and the absolute uniqueness of the human person involved in each individual situation,, the values must be interpreted by contextualising them in the environment and the individual circumstances, on the understanding that every aspect of the situation being acted upon, both technical and specifically human, demand careful appraisal.

This can also be achieved by seeking ethical *advice* with a clearly-defined working methodology that identifies the essential elements on which to reflect, whether clinical, ethical or responsibility-related, to provide input to best define the decisions and focus attention on the consequences. Counselling of this type offers benchmarks and direction for both the patient and the health professional in their efforts to play a part in taking decisions regarding their illness.

The purpose of this consultancy work by an individual consultant who is an expert in clinical bioethics or, better still, working jointly with the Ethics Committee in order to take the best interdisciplinary approach, must be to share the critical ethical pathways in order to establish

a commonly shared moral language between health professionals and patients, also offering support for treatment planning. The aim is to safeguard the right to autonomy of anyone requesting medical intervention to safeguard their health, as well as the professional integrity of the people working in the service of life, with the help of benchmarks 'other' than the narrow, indispensable, technical skills.

The importance of formation

It is essential not only to provide the desirable initial training of health professionals who deal extensively with these issues, but also subsequent continuing training based on a sound understanding of the complexity and the realisation that dependency and interdependence constitute an integral part of human nature.

Participation (empathy, active listening, catharsis), experience, overcoming paternalism, multi-disciplinarity, a holistic vision of existence, authenticity, and the rejection of reductionism, are the canons of a new word-based medicine and, in various ways, desirable guidelines for lifelong training for health care professionals.

Training must therefore not only clarify the wholly particular scientific aspects of everything having to do with the sound medical management of the end of life, but also the following points:

- (a) the role of the medical profession: who should provide medical formation, and how doctors are trained in a renewed relationship of care to prevent a pre-defined social culture from creating the mindset of future generations;
- b) moving beyond an extreme exaggeration of the autonomy of those involved in the relationship (which generates defensive medicine) by restoring a relationship of "bringing benefit in trust" to support organisational efforts that promote relations of a therapeutic covenant and properly addresses the issue of aggressive and futile treatment;
- c) the role of people in rethinking not only their own death, but also their state of ontological non-self-sufficiency for a sound education in the theory of complexity, in the realisation that closely interconnected autonomy and dependence reveal the human and relational face of dignity and freedom;

d) the role of the health service in really predicting the length of care needed – and the cost to be included in the national budget – which would otherwise only remain a nice theoretical concept;

(e) the role of ethical consultancy and ethics committees in supporting and motivating decisions;

(f) the role of facilities in intervening positively in support of particularly frail patients, such as protected discharges with continuity of care or with proper and early access to palliative care, also in terms of simultaneous care.

The urgent need to learn how to communicate

At the conclusion of the Order's first World Bioethics Congress of the Order in Madrid, in 2017, the Spanish journalist, Fernando Onega, expressed his gratitude at having understood, in a crescendo of positions voiced during the entire congress, that the Hospitaller Order of St. John of God sees Bioethics as a way to help create more humane and fair societies. The Hospitaller Order, he said, works with and for people who are the focus of their concerns and give meaning to their militant work against hostility, selfishness and ethical relativism. It is an institution, probably unique in the world, with a history of testimony and example.

While expressing delight at having been able to hear such powerful attacks on marginalisation and any kind of sensational ethics, and on social exclusion and the new forms of poverty – brought about by not only economic but also cultural causes – and happy to have discovered so much wealth spread across the five continents, Onega also scolded the Order on only one account: not knowing how to communicate it through a painstaking effort to disseminate its message.

We must seize on this important stimulus by taking up the challenge to be "an ethical benchmark and forum ", not only as practitioners but also promoters of a society that focuses its attention on the human being and human dignity, defending people against suffering, socially integrating the most disadvantaged people, and working to build a better quality of life, denouncing what the Prior General called "a soul-less society" in his address to the Congress: being the Good Samaritan is the greatest of all revolutions, and entails positioning itself at the centre of the world fashioned by hospitality by filling the word 'dignity' with

meaningful content, never forgetting that all men and women are born with an intrinsic dignity.

We have to learn to become witnesses not only in our centres and facilities, but also by spreading our values and know-how, endeavouring to establish a dialogue with those who live in society between the Church, with its indefeasible core principles, and the scientific community which exerts pressure and constraints. It is necessary to support a permanent state of dialogue, without rejecting scientific progress but also without passively taking it on board, in order to continue to perform the work begun by St. John of God.

Conclusions

The great anthropological and cultural, ethical and economic, social and personal challenge regarding end-of-life issues requires us to give prominence to appraising life itself in terms of its possible limitations, and reflecting on the ethics of care and responsibility for each other.

The scenario in which we find ourselves requires us to accept the challenge of the complexity of modern society by addressing decisions of "high" transcultural mediation within a "plural" society. The best way of doing this is by trying to implement an operational patient reception plan that tends to prevent any requests that might give rise to moral conflicts in our Centres..

It is essential to *appreciate the value* of relationships, of welcoming family members and the time spent on communicating as part of the time spent on caring. But it is equally important to *educate* people to relate, and learn to *communicate* decisions based on our values.

Confronted by a social pressure that seems to be moving in the direction of recognising the voluntary interruption of life as a right that we may demand, we have to struggle to highlight and grasp the positive aspects that can result from sound ethical clinical practice directed to respect of life itself, both enabling doctors to refuse to administer a treatment that is not respectful of life, and allowing patients to be properly accompanied towards the end of their lives. A great deal of effort can be invested in formation and training on this aspect, on the assumption that the patient's decision-making autonomy and the doctor's responsibility are on the same plane, while developing in different ways and with different criteria.

It is only in an abstract universe that the patient chooses and the doctor supinely complies with the patient's wishes; but what happens in the real world is quite different, and often makes us respond to requests made due to loneliness brought about by the progress-driven

society we live in. Reality shows us suffering which is also questioning the meaning of life, and the doctor's responsibility to respond based on science and conscience. We have to respond to this social demand, however it may be taken up in legislation, by taking bold organisational decisions, to ensure that medical responsibility is not belittled to become a bureaucratic, contractual, rationalistic and efficiency-based action – in the name of what is certainly a imposed desire to replace an increasingly disregarded right not to be left alone to face death with the right to choose.

What is at stake is the present and future of our own - unique and unrepeatable – lives, and of human solidarity.