



OPINION OF THE WORKING GROUP ON ETHICS IN RESEARCH AND MEDICINE ON PALLIATIVE CARE IN THE EUROPEAN UNION



© COMECE – February 2016
(Translated from French)



*Secretariat of the Commission
of the Bishops' Conferences
of the European Community*

Square de Meeûs 19 | B-1050 Brussels (Belgium)
Tel. +32 (0)2 235 05 10 | Fax +32 (0)2 230 33 34
www.comece.eu | comece@comece.eu

**Opinion of the Working Group on
Ethics in Research and Medicine on
PALLIATIVE CARE IN
THE EUROPEAN UNION**



TABLE OF CONTENTS

1	THE ORIGIN OF PALLIATIVE CARE	3
2	THE EVOLUTION OF PALLIATIVE CARE IN EUROPE	5
3	A DEFINITION OF PALLIATIVE CARE	7
4	THE MERITS OF PALLIATIVE CARE	9
5	LISTENING TO THOSE WHO ARE SUFFERING	12
6	USING SEDATIVE DRUGS	14
7	GUARANTEEING ACCESS TO PALLIATIVE CARE	16
8	A MAJOR OBSTACLE: DODGING DEATH	18
9	LIMITING OR WITHHOLDING TREATMENTS	19
10	TRAINING IN PALLIATIVE CARE	22
11	PROVIDING CARE WITHOUT HASTENING DEATH	24
	CONCLUSIONS	26
	LIST OF MEMBERS	27



© COMECE – February 2016
(Translated from French)

Square de Meeûs 19 | B-1050 Brussels (Belgium)
Tel. +32 (0)2 235 05 10 | Fax +32 (0)2 230 33 34
www.comece.eu | comece@comece.eu

**OPINION ON
PALLIATIVE CARE
IN THE EUROPEAN UNION**

1. THE ORIGIN OF PALLIATIVE CARE

“Palliative care in the context of advanced disease and end-of-life care in the final months and weeks of life represents the last phase of health and social care for citizens before their death. These are matters of huge importance which create enormous challenges for health professionals, patients, families, and policy-makers. The acceptance of death as an unavoidable outcome and the inclusion of it in a care system whose pre-eminent goals are cure and rehabilitation is a complex matter. When death is seen as a medical failure rather than a natural inevitability, then supporting end-of-life patients and their loved ones with their physical and mental needs becomes problematic. For most of the 20th century, this situation was the reality throughout the world. However, in the late 1960s this began to change. In 1967 Cicely Saunders founded St Christopher’s Hospice in South London, the first modern hospice in England, combining clinical care, psychological support, education and research”¹.

These are the opening words to the report commissioned by the European Parliament on palliative care in the European Union. It recognises the crucial role played by one woman, who trained as first a nurse, then a social worker and finally as a doctor, who managed to revolutionise the care of terminally ill patients suffering in agony.

Combining her work as social worker with her home visits to the sick as a volunteer, Cicely Saunders discovered in the years immediately following the Second World War the shortcomings in English hospitals regarding pain relief, especially for patients in the advanced stages of cancer. In 1948 she regularly visited David Tasma, a cancer patient and survivor of the Warsaw Ghetto, who was dying of cancer and experiencing extreme pain and symptoms that were very badly managed by the medical practice of those days. He also felt an urgent need to recount his life story and tell people that he was dying before his time. While listening to him, Cicely Saunders discovered the reality of physical pain endured by many patients, made even greater by psychological and spiritual anguish, which led her later on to coin the term “total pain”. Deeply influenced by this discovery, she decided to devote her life to relieving such suffering and then embarked on her studies to become a doctor.

After qualifying as a doctor, she was put in charge of a hospital service at St Joseph’s Hospice that cared for patients suffering from malignant tumours in their advanced

¹ Policy Department Economic and Scientific Policy, *Palliative Care in the European Union*, European Parliament, 2008, http://www.europarl.europa.eu/RegData/etudes/etudes/join/2008/404899/IPOL-ENVI_ET%282008%29404899_EN.pdf.



phase. She showed that, together with carefully listening to the patient, the regular administration of powerful painkilling drugs such as morphine, with dosage and frequency calculated to soothe and even prevent all pain, and also paying attention to various other symptoms, enabled the patient find effective relief without creating either drug-dependency or life-threatening respiratory depression, which were deemed inevitable consequences of the effective and prolonged use of such drugs².

Drawing upon this experience, nineteen years after her meeting with David Tasma and having collected the requisite funds, Dr Saunders finally opened St Christopher's Hospice in 1967. Its mission was principally to receive terminally ill cancer patients suffering from pain. The institutional form she chose was that of a "charitable foundation" working outside the British National Health Service.

Cicely Saunders' initiative quickly became established in the United Kingdom and in Ireland. By 1977, twenty-six Hospices had opened their doors, all based on the St Christopher's Hospice model. That was the start of what came to be known as "The Hospice Movement"³.

Since both the term and the institutional form of "Hospice" had negative connotations in French-speaking countries, Dr Balfour Mount, who had himself trained at St Christopher's Hospice, decided to change the terminology. Back in Quebec in 1975, he opened a care centre, fully integrated in the Montreal University Hospital, for the treatment of "end-of-life" patients in pain. This included a 12-bed unit for inpatients, a homecare service and a mobile unit that could be consulted by all services in the hospital. To define the care being given, he chose the term "palliative care", and to describe this kind of care at institutional level he used the term "palliative care unit"⁴.

2 Cf. Avril Jackson, «Histoire et rayonnement mondial», in: D. JACQUEMIN (dir.), *Manuel de soins palliatifs*, 2nd édition, Paris, Dunod, 2001, p. 21-30.

3 Avril Jackson, op.cit., p. 26.

4 Cf. Balfour M. Mount, "The problem of caring for the dying in a general hospital; the palliative care unit as a possible solution", *Canadian Medical Association Journal*, Vol. 115, n° 2, July 17, 1976, pp. 119-121.

2. THE EVOLUTION OF PALLIATIVE CARE IN EUROPE

Since 1975, there are two parallel terminologies, centralised around the terms “Hospice” and “palliative care”. “Hospice” describes initially an independent hospital able to accommodate several dozen end-of-life inpatients, whereas the term “palliative” describes the type of care provided for these patients. “*The hospice is a specific care centre for terminally ill patients, where the patients receive treatment (known as ‘palliative care’) to help relieve pain and other symptoms causing discomfort*”⁵.

But these terms have come to overlap each other, and what some countries call “palliative care” other countries call “hospice care”. Other differences have arisen, depending on the chosen institutional forms. “*What is understood by the term ‘Hospice’ or how resources such as ‘Home Care’ and ‘Inpatient Unit’ are defined and quantified, varies considerably between different countries [of the continent of Europe] and between different regions*”⁶. This diversity in terminology and the differences in understanding of the key concepts of palliative care⁷ do not make it easy to adopt terms with a precise meaning in the different languages of the EU Member States; unfortunately this can cause some confusion⁸.

In Europe, beyond the borders of the United Kingdom and Ireland, hospices and palliative care units began spreading, firstly in Norway and Sweden, then gradually in all countries. Founded by 42 people in 1988, the European Association for Palliative Care nowadays represents the interests of over 50,000 healthcare professionals and volunteer carers spread out over 40 countries⁹. In 2003, the Council of Europe’s Committee of Ministers adopted a Recommendation¹⁰ which regards palliative care as an essential service for the population and recognises that,

5 *Palliative Care in the European Union*, op.cit., 2.1.1.

6 Carlos Centeno, David Clark, Thomas Lynch et al., “Facts and indicators on palliative care development in 52 countries of the WHO European region: results of an EAPC task force”, *Palliative Medicine*, 2007 00: 1–9.

7 Lukas Radbruch, Palliative care in Europe: experiences and the future, *European Journal of Palliative Care*, 2008, t. 15, Nr 4, pp. 186–189.

8 European Association for Palliative Care, “White Paper on standards and norms for hospice and palliative care in Europe”, Part 1, *European Journal of Palliative Care*, 2009, 16 (6), pp. 278–289.

9 *Palliative Care in the European Union*, op.cit., 1.1.

10 Council of Europe, Recommendation of the Committee of Ministers to the Member States on the organisation of palliative care, 12 November 2003, http://www.coe.int/t/dg3/health/Source/Rec%282003%2924_en.pdf



6 | CHAPTER 2

although the major part of national health budgets is spent on treating people in the final years of their lives, it is not certain that this care provided is necessarily the most appropriate for their needs. The report notes the huge disparities in access to and quality of palliative care right across Europe and urges every country to draw up national palliative care development plans. These recommendations appear to have borne fruit. In 2008 every single EU Member State had palliative care services, although in a few countries these were reduced to a handful of initiatives that were largely inadequate, given the size of their populations¹¹.

¹¹ *Palliative Care in the European Union*, report cited above, Executive summary, 1.2.

3. A DEFINITION OF PALLIATIVE CARE

At the outset, the goal of palliative care (whether provided in “Hospices” or through palliative care units) was to provide relief for the suffering of cancer patients at the advanced stage, and also to provide support for sundry patients suffering from degenerative nerve diseases. It gradually became clear to political and healthcare decision-makers that this goal was too narrow and that many other people were also entitled to benefit from this kind of care, people who “*have serious illnesses, are in pain or are in a state of great despair*”¹². In 2002, the World Health Organization (WHO) put forward a definition which has now become a universally acknowledged reference:

“Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- *provides relief from pain and other distressing symptoms;*
- *affirms life and regards dying as a normal process;*
- *intends neither to hasten or postpone death;*
- *integrates the psychological and spiritual aspects of patient care;*
- *offers a support system to help patients live as actively as possible until death;*
- *offers a support system to help the family cope during the patients illness and in their own bereavement;*
- *uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;*
- *will enhance quality of life, and may also positively influence the course of illness;*
- *is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications*¹³.

12 Parliamentary Assembly of the Council of Europe, Resolution 1649, Palliative care – a model for innovative health and social policies, 28 January 2009, http://www.coe.int/t/dg3/healthbioethic/texts_and_documents/INF_2014_5_vol_II_textes_%20CoE_%20bio%C3%A9thique_E%20%282%29.pdf.

13 WHO Definition of Palliative Care, <http://www.who.int/cancer/palliative/definition/en/>.



This definition underlines the need to take into account the wide array of elements of human suffering; it embraces the support to be extended to the patient's family, defines what objectives are to be pursued and those to be excluded. It does not reserve palliative care only for cancer patients¹⁴.

It points out that it would be regrettable if too strong a contrast were made between actions aimed at diagnosis and cure against those forming part of palliative care, since the latter may be provided "in conjunction with other therapies that are designed to prolong life". Palliative care should therefore no longer be limited to "end-of-life care". To avoid any such interpretation, and to help people understand that such care can and must be put in place well before the final days of life, perhaps from now on the terminology should be changed and the expression "supportive care" used instead, or other similar expressions.

14 Cf. European Commission, Directorate General for Health and Food Safety, Palliative Care in the Europe Union: Follow-up to informal Council discussions and proposals for a European Union framework of action, 2014, §4.

4. THE MERITS OF PALLIATIVE CARE

Cicely Saunders today may be regarded as a radical innovator, because she was introducing methods of care that were radically new in the 1960s. She had no hesitation in using major painkillers – with caution but without any reticence – especially morphine and its derivatives, while clearly aiming not only to soothe but even to prevent the acute pain which dying patients can find so hard to bear. Contrary to the beliefs firmly entrenched in medical circles and in public opinion, she demonstrated that the proper handling of these drugs avoided the creation of any narcotics addiction or any suddenly fatal respiratory depression, consequences that so many doctors of that period feared¹⁵.

This would then remove all the objections that had for over a century been raised on medical grounds¹⁶ with respect to these painkillers. Thereafter it became almost an obligation for doctors to use them for the benefit of any patient in pain who asked for them and for whom these drugs were medically indicated. Historically, though, doctors have always believed that their mission should be to promote health, combat disease and relieve suffering, using appropriate means. Once effective painkillers for use against acute pain became acceptable for use, doctors needed to know how to use them wisely.

Some end-of-life situations are marked by acute suffering which, if not relieved, can crush the person experiencing it with deleterious somatic, psychic and spiritual repercussions. This is what prompted Pope Pius XII, ten years before the opening of St Christopher's Hospice, to take a firm stand on the usage of painkilling drugs and especially of "narcotics". In a speech¹⁷ that would later on attract a great deal of commentary, he recalled that there were Christians who elected not to ask for relief from their pain so that they could unite themselves voluntarily to Christ's suffering on the cross. This could be the testimony of immense faith and great love. Pius XII praised this attitude, yet still recommended that a healthy degree of caution should be followed. He remarked that there were other ways open to those who wished "to love God and serve him in all things", which forms the basis of Christian life. This most often leads to a search for ways of avoiding acute physical pain. In fact,

15 Cf. Cicely Saunders and Mary Baines, *Living with dying. The management of terminal disease*, Oxford University Press, 1983, 3.

16 Cf. R. Brouillard, «Causerie de morale. Stupéfiants et anesthésiques», *Études*, t.199, 20 April 1929, pp. 178-198 (in French).

17 Speech of Pope Pius XII replying to three religious and moral questions relating to pain management, 24 February 1957, https://w2.vatican.va/content/pius-xii/fr/speeches/1957/documents/hf_p-xii_spe_19570224_anestesiologia.html (in French and Spanish).



*“ultimately, pain prevents the attainment of goods and best interests. It may be that it is better for such a person in such a determined and practical situation; but in general the damage resulting from pain forces men to defend themselves against it”*¹⁸.

With regard to terminally ill patients, Pius XII added *“the growth of God’s love and submission to His will does not emerge from suffering even when it is accepted, but from voluntary intention supported by grace; this intention in many people who are dying may become stronger and become more alive if their suffering is relieved, because that is what aggravates the state of feebleness and physical exhaustion, hampers the surge of the soul and undermines moral forces instead of supporting them. In contrast, the blocking of pain procures a bodily and mental relaxation, makes it easier to pray and enables a more generous gift of the self”*¹⁹.

This formal statement is about the type of pain that would lead, ten years later, to the creation of St Christopher’s Hospice, *“unbearable pain [caused] for example by inoperable cancers or by incurable diseases”*²⁰. This order of pain would justify the use of “narcotics” considered in those days as agents that would reduce consciousness and shorten the life span. Experience has since then demonstrated that in most cases, if handled correctly the major painkillers such as morphine in no way reduce the alertness of the patient, nor do they shorten his life. Their use can then thereafter no longer be restricted to the use of “unbearable” pain but it remains vital, as the World Health Organization recommends²¹, that the power of the painkiller should be dosed in proportion to the intensity of the pain to be relieved.

For a long time, the use of these major painkillers, currently referred to under the term “opioids”, came up against legal and regulatory obstacles. In 2003, the Council of Europe’s Recommendation pointed to *“enormous resistance arising from ill informed and unfounded fears concerning their use. Exaggerated concerns regarding such issues as dependence, addiction, tolerance and respiratory depression hampered their appropriate introduction to medical practice”*²². The report commissioned by the European Parliament mentions that in several countries bureaucratic barriers

18 Pius XII, op.cit., I. See also: Congregation for Doctrine of the Faith, Declaration «Iura et Bona» on euthanasia, 1980, 3, http://www.vatican.va/roman_curia/congregations/cfaith/documents/rc_con_cfaith_doc_19800505_euthanasia_en.html.

19 Pius XII, op.cit., III.

20 *Idem*.

21 Arthritis Research UK, Painkillers (analgesics), <http://www.arthritisresearchuk.org/arthritis-information/drugs/painkillers/what-it-is.aspx>.

22 Council of Europe, Recommendation of 12 November 2003, op.cit., n° 8.

still existed in 2008 making it difficult to get access to the drugs, even in cases where fully justified for medical reasons²³. While prescribing greater vigilance to prevent any abusive use of these products, “*legislation should make opioids and other drugs accessible in a range of formulations and dosages for medical use. The fear of abuse should not hinder access to necessary and effective medication*”²⁴.

All this does not stop a general trend in our societies to peddle the myth of an existence that would be entirely free of any suffering. In 1989, during the 7th Symposium of European bishops, Mgr Karl Lehmann warned against the desire to avoid all suffering. “*Anaesthetising life is a fundamental enemy of human society*”²⁵. He was probably thinking about the abusive use of painkillers, even more of narcotic drugs, in the desire to escape all anxiety and awareness of hardship. Indeed, pain is not the only source of suffering.

23 *Palliative Care in the European Union*, op.cit, 2.6.2.

24 Council of Europe, Recommendation of 12 November 2003, op.cit, General considerations, III, 5.

25 Mgr Karl Lehmann, Address to the 7th Symposium of the Council of European Bishops, Rome, 12-17 October 1989, *La Documentation Catholique*, 19 novembre 1989, pp. 1006-1007.



5. LISTENING TO THOSE WHO ARE SUFFERING

“The suffering of those who are facing death is not limited to physical pain. Suffering from a serious illness means that one becomes subject to a brutal trial of bodily weakness, of the loss of physical and even mental powers, and means depending upon other people. Dying implies a painful labour of divesting oneself of the self, of tearing away from everything that makes up concrete existence, of becoming separated from the people one loves. It means being confronted with the prospect of the ultimate journey. This can become a source of distress, even of despair, if no support is given to those who are going through such a crisis. For believers, faith in a God of love and hope does not protect them from this suffering. The Bible itself is full of the clamour and supplication of those who are undergoing such a trial”²⁶.

Also fully included in palliative care are *“the emotional, spiritual and practical support given to the patient and members of his family”²⁷. “The objective of palliative care is to alleviate suffering in the final stages of illness and at the same time to ensure the patient appropriate human accompaniment”²⁸.*

Once that pain has been relieved, other forms of suffering can then reveal themselves. The patient may feel disquiet, fear, anxiety, anger, guilt or desire for reconciliation regarding previous conflicts that have not reached closure; there is also loss of confidence, a feeling of isolation and being abandoned: he may often wonder why he is going through such affliction, on the meaning of his life, on death and on life after death²⁹. He may be overwhelmed by all this. If the people who surround him are willing to listen with understanding, this may enable him in many cases to be able to articulate his concerns, to come out of his isolation, to find some balm for his anxiety. He may even be able to look back on his life, sometimes making some sense of it all and from this seeing the main patterns, ratifying his key choices, and then seeking to make peace with others and with God Himself.

26 Permanent Council of the Bishops' Conference of France, *Respecter l'homme proche de sa mort*, 23 septembre 1991, <http://www.eglise.catholique.fr/conference-des-veques-de-france/textes-et-declarations/369211-respecter-lhomme-proche-de-sa-mort/> (in French).

27 Catholic Bishops' Conference of England & Wales, *A Practical Guide to the Spiritual Care of the Dying Person*, Inc. Catholic Truth Society, 2010, <http://www.catholic-ew.org.uk/Home/News/2010/Catholic-Bishops-Conference-launches-A-Practical-Guide-to-the-Spiritual-Care-of-the-Dying-Person>.

28 Pope Francis, Speech to the participants in the Plenary of the Pontifical Academy for Life, 5 March 2015. See also John-Paul II, *Evangelium Vitae*, 1995, n° 65, http://w2.vatican.va/content/john-paul-ii/en/encyclicals/documents/hf_jp-ii_enc_25031995_evangelium-vitae.html.

29 Cf. *A Practical Guide to the Spiritual Care of the Dying Person*, op.cit., 1.

During this process, many patients often manage to find new meaning in their lives.

This spiritual dimension of care giving at the core of palliative care is nowadays being extensively researched. The European Association for Palliative Care has set up a working group on this theme³⁰. Spiritual support can take a religious form. Every patient who asks for it is entitled to help from a representative of his religious faith. But all healthcare professionals and all family members are also called upon to participate in this support, even if it is just to show empathy and to be a good listener. “*But providing spiritual care is not the exclusive domain of chaplains or chaplaincy teams*”³¹. However it must be recognized that this close contact with patients suffering from illnesses that have become incurable and are becoming terminal “*inevitably mobilises innermost resources, conscious and unconscious, of intelligence and emotion; it consumes ‘internal energy’ that sometimes exceeds what can be controlled*”³².

Medicine nowadays has drugs available for reducing unease and anxiety. In many cases, a cautious and measured use of anxiolytics allows acute anxiety to be capped, and makes it easier to communicate with the patient and to interact with him. But this might turn out to be an escape route for healthcare professionals if they routinely use these products in order to avoid contact with patients who are worried or in distress³³.

30 European Association for Palliative Care (EAPC), *Taskforce on Spiritual Care in Palliative Care*, <http://www.eapcnet.eu/Themes/Clinicalcare/Spiritualcareinpalliativecare.aspx>.

31 *A Practical Guide to the Spiritual Care of the Dying Person*, op. cit., Introduction.

32 Bernard Matray, *La présence et le respect*, Paris, Desclée de Brouwer, 2004, p. 192 (in French).

33 Cf. Jean-François Richard, «Entendre et soutenir la personne inquiète en fin de vie», in: *L'inquiétude en fin de vie*, Médiasèvres n° 150, 2009, <http://www.jesuites.com/actu/edition/verspieren.htm>.



6. USING SEDATIVE DRUGS

In some cases, it seems impossible to avoid a patient suffering from intense pain without using what will from now on be referred to as “sedation”, which can be defined thus: “*Seeking, by clinical means, a reduction in alertness that can go as far as the loss of consciousness. Its object is to reduce or to eliminate the perception of a situation that the patient views as intolerable while all available resources appropriate to the situation have been recommended to him and/or put in place, without however obtaining the desired relief*”³⁴. It may be applied intermittently, temporarily or continuously. Its depth, meaning the degree of reduction of the patient’s alertness (lucidity) can be varied as appropriate for the patient.

The research carried out in the past few years tends to confirm the absence of unexpected premature deaths³⁵ when patients are sedated in accordance with good professional practice³⁶. However, sedation reduces the patient’s consciousness and awareness of his environment, and also hampers his ability to express himself. Yet he must not be deprived of this “*consciousness without a serious reason*”³⁷. It is essential that sedation should only be used if there are pressing reasons, in cases of suffering resistant to other therapies and where the pain is almost unbearable for the patient; the appropriate level and duration of sedation are calculated in function of the source and nature of the intense pain. Using sedation outside such situations would not be justified³⁸, and would place unnecessary obstacles to the contacts between the patient and his family, and could lead to the healthcare professionals losing interest in patients with reduced powers of communication, and consequently to the excessive prescription of sedative drugs shortening life in a way that could be likened to “a slow euthanasia”³⁹.

34 Société Française d’Accompagnement et de Soins palliatifs (SFAP), *Sédation pour détresse en phase terminale et dans des situations spécifiques et complexes: Recommandations dans les situations spécifiques et complexes*, Encadré 1. Définition de la sédation (in French), <http://www.sfap.org/system/files/sedation-situations-specifiques-complexes.pdf>.

35 Cf. M. Maltoni, E. Scarpi, M. Rosati, “Sedation in end-of-life care and survival: a systematic review”, *Journal of Clinical Oncology*, 2012, April 20, t. 30, n° 12, pp. 1378-1383, <http://www.ncbi.nlm.nih.gov/pubmed/22412129>.

36 SFAP, recommendations cited.

37 Pius XII, op.cit., II. See also *A Practical Guide to the Spiritual Care of the Dying Person*, declaration cited above, 2.12.

38 Nathan I Cherny, Lukas Radbruck and the Board of EAPC, “European Association of Palliative Care (EAPC) recommended framework for the use of sedation in palliative care”, *Palliative Care*, 2009, t. 23, Nr 7, pp. 581-593, <http://www.eapcnet.eu/LinkClick.aspx?fileticket=RKDokneiDJc%3D&tabid=38>.

39 *Idem*.

Brief periods of sedation allow the patient not to be aware of an episode of his illness or therapy that would otherwise have been gruelling. In the end-of-life period, events such as a catastrophic haemorrhage or a terminal refractory to standard treatment acute respiratory distress can occur that would justify the use of deep continuous sedation administered to avoid the patient being aware of something that would inspire genuine terror in him. Very often such a decision has to be taken on the spot, but it is advisable that it should have been anticipated and discussed in advance⁴⁰. Furthermore, after necessary assessment, informing the patient and getting his consent, or – if that is impossible – after consultation with his family members, sedation may and should normally be envisaged in the final days of life if there are symptoms that the patient deems intolerable and which are refractory to all treatment⁴¹.

Some studies employ the expression “terminal sedation”⁴². This is the source of a great deal of ambiguity. Either this is a dubious shortcut for the expression “sedation in terminal phase of the disease” or it is used to open the way implicitly for sedative practices conducted not only to spare the patient from feeling pain but also to hasten the moment of death deliberately. But such forms of sedation deserve to be qualified as acts of euthanasia.

40 *Ibidem*.

41 SFAP, *Sédation pour détresse en phase terminale et dans des situations spécifiques et complexes. Recommandations chez l'adulte et spécificités au domicile et en gériatrie*, <http://www.sfap.org/system/files/sedation-phase-terminale.pdf>.

42 Johannes J M van Delden, “*Terminal sedation: source of a restless ethical debate*”, *Journal of Medical Ethics*, 2007, Apr., t. 33, Nr 4, pp. 187-188.



7. GUARANTEEING ACCESS TO PALLIATIVE CARE

Compassion towards patients suffering from deadly diseases and solidarity with them is the spur to advocate for a widespread development of palliative care and access to it. The Recommendation of the Committee of Ministers of the Council of Europe in 2003 acknowledged that “*any person who is in need of palliative care should be able to access it without undue delay, in a setting which is, as far as reasonably feasible, consistent with his or her needs and preferences*”⁴³.

Despite this strong recommendation, there are still some flagrant disparities between countries and between regions inside each country, which are listed in the report commissioned by the European Parliament⁴⁴. According to some observers, “*current reviews reveal a persistent abyss between Member states’ policies on this issue*”⁴⁵.

The time is ripe to enshrine in the legislation of each Member State a right to access to palliative care for every sick person whose condition requires it, to ensure that this right is respected and therefore to develop palliative care to the extent necessary, and to this end to create a sufficient number of institutions adapted to the needs and the culture of the country and to grant them the resources and the means that are necessary. This requires that political decision-makers in every country should be aware of their health system’s deficiencies in this field, and they should have a firm desire to provide a solution. This mobilisation of public authorities depends partly on the reaction of the population which currently remains, in too many countries, poorly informed and insufficiently aware.

What is more, Europe is ageing. In a recent report on ageing published by the European Commission⁴⁶, a forecast predicts that in 2060 the proportion of people aged 80 and over in the EU28 will pass from 5% to 12% of the population, while the proportion of 15 – 64 years will fall, dropping from 66% to 57%. In this scenario, the care of old people, especially palliative care, will acquire a growing importance in the health systems of Member States. It is vital to acknowledge this, to spread awareness in the general public, to develop the requisite health and social institutions, and to train good

43 Council of Europe, Recommendation of 12 November 2003, cited above, I, Fundamental principles.

44 *Palliative Care in the European Union*, op.cit..

45 Jose M. Martin-Moreno, *Developing palliative care in Europe*, Reflection paper for the EU Health Council, 22-23 September 2014.

46 European Commission, *The 2015 Ageing Report - Underlying Assumptions and Projection Methodologies*, 2014, http://ec.europa.eu/economy_finance/publications/european_economy/2014/pdf/ee8_en.pdf.

healthcare workers in sufficient number.

The organisation of health systems lies within the competence of the EU Member States, but this does not remove from European bodies all responsibility in the field of end-of-life care. They have a legitimate call to work to assess the needs and the actions undertaken, to encourage and stimulate the exchange of ideas, experience and initiatives, competencies and resources among the various EU countries, and thereby to contribute to the correction of disparities⁴⁷. In September 2014, an informal meeting of the Council of European health ministers during the Italian Presidency tackled the question of pain therapy and palliative care⁴⁸. The Commission is preparing a European framework for palliative care. Various research projects have also been developed under the auspices of and with funding from the European Union⁴⁹. In 2014, a “European Declaration on Palliative Care” was launched in Brussels under the form of a petition during the Final Conference of the Impact and Euro Impact projects. This Declaration clearly asks that measures should be ensured “*that allow patients and their family timely access to palliative care consistent with their level of need, regardless of diagnosis, age, prognosis estimated life expectancy or care setting*” and also for “*access to specialist multidisciplinary palliative care services or teams in all health care settings*”⁵⁰.

Particular attention should be paid to groups of people who are especially vulnerable, to members of ethnic minorities⁵¹, to children suffering from incurable diseases, to old people with their specific needs⁵² and most particularly to those who are accommodated in medical-social institutions for whom in certain countries the organisation of care is especially problematic. There is no justification for limiting palliative care just to patients suffering from cancer, as was the case when it was first being developed. “*It has until now been a precious accompaniment for cancer patients, but today there is a great variety of diseases characterized by chronic progressive deterioration, often linked to old age, which can benefit from this type of assistance*”⁵³.

47 Cf. Jose M. Martin-Moreno, *Developing palliative care in Europe*, article cited above.

48 For the summary of the conclusions of the ministers’ meetings see <http://italia2014.eu/en/news/post/conclusioni-informale-salute/>.

49 See for example, the “Impact” project (<http://www.impactpalliativecare.eu/Default.aspx>) and the “Euro Impact” project (<http://www.euro-impact.eu/>).

50 European Declaration on Palliative Care, 2004, 3 and 4, <http://www.palliativecare2020.eu/declaration/index.php>.

51 *Idem*.

52 Cf. World Health Organisation, Regional Office for Europe, *Palliative Care for Older people, Recommendations*, p. 52, http://www.euro.who.int/__data/assets/pdf_file/0017/143153/e95052.pdf.

53 Pope Francis, Speech of 5 March 2015, cited above.



8. A MAJOR OBSTACLE: DODGING DEATH

The fact that, 50 years after being invented and despite the public recognition of its merits and the need for it, palliative care is not yet sufficiently available in the majority of the Member States, reveals that its evolution has been encountering major obstacles.

Already in 1989, at their symposium the European bishops had recognised the profound cultural changes which had changed our continent. They had observed that the effect of medical advances had, without anybody wanting this, been pushing childbirth and particularly death outside the home. This has led especially to losing the experience of being close to death and has helped strengthen the anguish experienced in the face of death. Besides, medicine cannot on its own explain the loosening of solidarity between the generations that is now noticeable. The major factor is to be found in the new modern lifestyles which have spread across Europe⁵⁴.

This evolution has been happening in Europe, to the extent that in most European countries the prospect of the finitude of human existence is pushed back “to the edge”⁵⁵ outside day-to-day concerns. The victories won by medicine allow any person to push back to ever more distant horizons the prospect of his own death. *“Moreover, there is a subtle but pervasive perception among many doctors that death is a medical failure, rather than a natural close to all life, which can lead to clinical objectives that favour cure over quality of life and create barriers for referrals to appropriate end-of-life care”*⁵⁶.

Moreover, at the outset palliative care was developed for patients at their end-of-life stage. For many Europeans, the prescription of palliative care is therefore perceived as an announcement that death is imminent. Thus, the term itself has become difficult to pronounce for many doctors, leading them to postpone any offer to provide such care, instead continuing for far too long to prescribe medical treatments that have become inadequate.

54 Cf. Cardinal Carlo Maria Martini, *Synthèse des travaux et orientations*, 7^o Symposium des évêques européens, *La Documentation Catholique*, 19 November 1989, pp. 1013-1020.

55 Cf. *A Practical Guide to the Spiritual Care of the Dying Person*, op. cit., 3.1.

56 Jose M. Martin-Moreno, *Developing palliative care in Europe*, op.cit., p. 3.

9. LIMITING OR WITHHOLDING TREATMENTS

When palliative care is put in place, one of the principal questions arising nowadays concerns successive curative care and palliative care, or otherwise using both at the same time. Cicely Saunders had right away recommended that these different types of care should not be set against each other, but that palliative care should be introduced, curative therapies maintained as long as they were appropriate, and that one learned when to gradually restrict or stop them⁵⁷. This has been forgotten, at least in certain countries which are today rediscovering the need for “*a consolidated and continuous concept of care, blending curative and palliative care together*”⁵⁸. This means that palliative care should be implemented as soon as it becomes necessary “*on the basis of need, not diagnosis or prognosis*”⁵⁹, while even curative therapies might still be deemed appropriate. But that also implies that these therapies should not be continued when it is clear they no longer benefit the patient.

In the thirty years following the Second World War, while medicine was constantly advancing in leaps and bounds, it seemed morally unacceptable to many doctors to stop any treatment which was still showing itself effective, even in a very limited way, for keeping a patient alive. Such a decision was therefore described as “passive euthanasia”. This vision of things led to the excesses that were condemned under the term “aggressive medical treatment”. The resulting protests led to the rediscovery of the ethical tradition which for centuries have fully recognised a patient’s right to refuse certain treatments, chiefly on the basis of a distinction between “ordinary” and “extraordinary” means of conserving life⁶⁰.

Studies since the 1970s have somewhat updated the terminology used, adapting it to new conditions, while still showing the aptness of the previous thinking⁶¹. That is what Pope John-Paul explicitly confirmed. “*Euthanasia must be distinguished*

57 Cicely Saunders and Mary Baines, *Living with dying. The management of terminal disease*, op. cit., Introduction.

58 Working Group ‘Fin de vie’ of the Bishops’ Conference of France “Ne prenons pas le problème à l’envers!”, 20 January 2015, I.6., <http://www.eglise.catholique.fr/conference-des-vevues-de-france/textes-et-declarations/389425-prenons-pas-probleme-lenvers/> (in French).

59 WHO, Worldwide Palliative Care Alliance, *Global Atlas of Palliative Care at the End of Life*, 2014, p. 7.

60 Daniel A. Cronin, “The Moral Law in Regard to the Ordinary and Extraordinary Means of Conserving Life”, in: *Conserving Human Life*, The Pope John XXIII Center, Braintree, MA, USA, 1989, pp. 1-145.

61 Cf. Pontifical Academy for Life, *Au chevet de la personne qui meurt. Orientations éthiques et pratiques*, Elio Sgreccia, Mame-Edifa, 2008.



*from the decision to forego so-called 'aggressive medical treatment', in other words, medical procedures which no longer correspond to the real situation of the patient, either because they are by now disproportionate to any expected results or because they impose an excessive burden on the patient and his family. In such situations, when death is clearly imminent and inevitable, one can in conscience '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'. (...) To forego extraordinary or disproportionate means is not the equivalent of suicide or euthanasia; it rather expresses acceptance of the human condition in the face of death"*⁶².

There has been much debate on the subject of "clinically assisted" hydration and nutrition, which use artificial supports to convey water and nutrients. "Clinically assisted" nutrition, requires a surgical intervention to place a «stoma» in the stoma or intestine, whereby it has often been described as a "medical treatment" and this qualification has often been cited in order to recommend this form of nutrition on the same level as "treatment" and to discontinue it at the same time as other medical treatments are withdrawn.

However, feeding a human being who has become dependent is a sign of attention, of acknowledgment of his belonging to the human community and of his dignity, a sign of attachment on the part of the family⁶³. Even when all curative treatment has been stopped, the patient still has to be fed and given water orally as long as that is still possible, as long as he is still able to assimilate whatever is offered to him, and as long as it does not cause him run any disproportionate risk, and as long as he does not refuse it. Difficulty in swallowing, or the risk of "pulmonary aspiration", gives no exoneration from the duty to provide assistance, as long as the patient retains his assimilation capacity, and that the food and water can be provided through simple means, that it is not too difficult or too restrictive for the patient, or does not incur any major risk⁶⁴.

The decision can be sensitive, and even controversial. In the absence of any risk of complications, as a general rule the nutrition and hydration of a patient by either oral or artificial means must be continued. But, as death approaches, or at the end

62 John-Paul II, *Evangelium Vitae*, op.cit., n° 65.

63 Cf. *A Practical Guide to the Spiritual Care of the Dying Person*, op.cit., 2.6.

64 Cf. John-Paul II, Speech to the participants in the international congress on "Life-sustaining treatments and vegetative state" promoted by the International Federation of Catholic Medical Associations, 20 March 2004. See also WG Bioethics, «Post-coma unresponsiveness commonly called 'vegetative state'», *Sciences and Ethics*, Vol. 2, COMECE, 2012, pp. 43-44.

of the final stages of Alzheimer's disease, very often nutrition using artificial means confers hardly any benefit and can even expose the patient to fatal complications⁶⁵. On a case by case basis, there should be an assessment of the situation and of the benefits of continuing the artificial nutrition, and the most appropriate decision should be taken after consulting the patient or talking to members of his family⁶⁶. In the same vein, as death approaches, too much hydration could provoke discomfort or even bring on regrettable complications⁶⁷. Caution is required in this field.

65 Cf. Marie de Saint-Hubert et al., «Soins palliatifs et fragilité. Maladie d'Alzheimer et maladies apparentées», in: D. Jacquemin and D. de Broucker (dir.), *Manuel de soins palliatifs*, 4^e édition, 2014, pp. 426-438.

66 Cf. A Practical Guide to the Spiritual Care of the Dying Person, op.cit., 2.6.

67 Cf. Didier de Broucker, Nutrition et hydratation: aspects éthiques en soins palliatifs, *Manuel de soins palliatifs*, 4^e édition, op. cit. pp. 1040-1044.



10. TRAINING IN PALLIATIVE CARE

One of the key issues in the development of palliative care is that of proper training, adapted to every culture, of the caregivers and volunteer workers involved. But, major disparities in this field can be seen between the Member States. The Council of Europe Recommendation highlights the need for structured education programmes integrated in the training curricula for all healthcare professionals. *“In many countries, three levels of education have been specified: a basic level, to be taught to all healthcare professionals, an intermediate level, to be taught to those within a profession who want to acquire specific expertise in palliative care without wanting to become palliative care specialists, and an advanced level, intended to those who do want to become specialists in palliative care”*⁶⁸. The requisite training includes the acquisition of competencies in pain management and controlling other symptoms and also learning how to approach and take into account the social, emotional and spiritual needs, how to support families before and after the patient dies, and how to work in a team⁶⁹.

This training demands the participation of professional caregivers who have gained their own experience, in different forms, of caring for terminally ill patients, and who have devoted a substantial part of their medical career to it. As a general rule, the development of palliative care depends upon the personal commitment of the caregivers who are sufficiently convinced of the importance of their task and who are ready to invest a lot of personal energy in it, to choose – against the trend of the ideals of modern-day medical profession – to care for patients for whom little hope remains in terms of cure or of remission. This brings them, day after day, to have face to face contacts with patients who are not going to get well and most of whom will die within a more or less brief period. This closeness can prove to be heavy to bear.

In order to volunteer for the work and in order to persevere permanently in this particular form of exercise, these health professionals need to be supported in various ways, by mutual esteem inside their unit team, the support of the institution itself where they work, and also by a genuine social recognition of the value and importance of their mission.

It is therefore vital that public opinion should be informed about the reality of palliative care and what it brings to patients who are about to die. The general

⁶⁸ Council of Europe, Recommendation of the Committee of Ministers, 12 November 2003, op.cit., n° 144.

⁶⁹ Cf. *Palliative Care in the European Union*, 2.3.1.

public should be persuaded that, as death approaches, pain is no longer inevitable and that a lot can be done to soothe the final moments of existence, thanks to the progress in palliative care and the commitment of the people who provide it.



11. PROVIDING CARE WITHOUT HASTENING DEATH

According to the definition given by the WHO and fully recognised by the European Association for Palliative care, “*palliative care provides relief from pain and other distressing symptoms, affirms life and regards dying as a normal process, intends neither to hasten nor to postpone death*”⁷⁰. Not more than the unreasonable obstinacy in fighting disease currently termed “aggressive medical treatment”, euthanasia (that is to say, all behaviour with the aim of provoking death in order to avoid suffering⁷¹) does not form any part of palliative care. It is vital to avoid all ambiguity on this subject. Intentionally bringing on the death of a patient, even if he asks for it, does not constitute caring for him.

In the same vein, warning is given against expressions such as “continuous palliative care” or “integrated palliative care” used particularly in countries where euthanasia has been depenalised, to designate care giving that does not exclude having recourse to this practice as a last resort, on the request of the patient⁷². These expressions are not neutral. Their effect and, without any doubt, their goal, is to mask the character of serious transgression which is the act of deliberately causing the death of another person⁷³. They help to trivialise euthanasia by leading it to be considered as just another end-of-life treatment among many, and even more so if one adds to it the notion of a “right to avoid unnecessary suffering”⁷⁴ and the evocation of the cost to society of caring for an ageing population.

70 Lukas Radbruch, Carlo Lege, Patrick Bahr et al., Euthanasia and physician-assisted suicide: A white paper from the European Association for Palliative Care, *Palliative Medicine*, 2015, <http://www.eapcnet.eu/LinkClick.aspx?fileticket=28Vb6OIn9SQ%3D>.

71 Cf. Reflection Group on Bioethics, Euthanasia, Opinion of 19 March 1998, *Sciences and Ethics*, COMECE, 2008, pp. 64-66. See also World Medical Association, Resolution on euthanasia, <http://www.wma.net/en/30publications/10policies/e13b/index.html>.

72 European Institute of Bioethics, Le modèle belge des «soins palliatifs intégraux» dénature-t-il la pratique des soins palliatifs?, <http://www.ieb-eib.org/fr/pdf/20150904-dossiers-euthanasie-et-soins-palliatifs.pdf>.

73 Cf. John-Paul II, *Evangelium Vitae*, op.cit, §65.

74 A draft Declaration was drawn up in this spirit and submitted to the European Parliament for signature in October 2015. It argued that “*All European citizens (...) who are in an advanced or terminal phase of an incurable illness causing unbearable physical pain or mental suffering that cannot be alleviated, should be able to benefit from medical assistance to end their life with dignity.*” Fortunately, at the end of three months it had gathered only 95 signatures, very far from the figure of 376 required by the Parliament to take it further, and so the proposal lapsed, <http://www.europarl.europa.eu/sides/getDoc.do?pubRef=-%2f%2fEP%2f%2fNONGML%2bWDECL%2bP8-DCL-2015-0055%2b0%2bDOC%2bDF%2bV0%2f%2fEN>.

They can also hamper the improvement of genuine palliative care. According to one doctor, describing the situation in her country, *“the diffusion of skills acquired in palliative care for the consideration of global suffering is highly inadequate and there are no funds for it. Research studies are not completed, particularly those looking at our capacity to approach without fleeing from the existential suffering of the most vulnerable, and even less into the best way of trying to respond to it. (...) The performance of euthanasia as a dignified and courageous solution creates havoc among our contemporaries, disfigures and hinders palliative care and, more broadly, the medical profession and society”*⁷⁵.

⁷⁵ Catherine Dorpchie, «L'euthanasie tue-t-elle les soins palliatifs?», *Les cahiers francophones de soins palliatifs*, 2013, vol. 13, n° 2, article quoted by the European Institute of Bioethics, dossier cited (in French).



CONCLUSIONS

With its origins in the meeting of a young woman with a man receiving inadequate relief from acute pain who was dying prematurely with the feeling that his life was being cut short, palliative care has shown itself to be a work of great humanity, demonstrating the solidarity of society with those of its members undergoing hardship, showing consideration of their vulnerability and recognition of their dignity⁷⁶. It deserves to be actively supported in such a way that it can be developed and respond to the growing needs of ageing societies that include a constantly increasing proportion of people suffering from chronic diseases and in need of palliative care.

Let us hope that it will remain faithful to its original intention, combining medical competence with solicitude for people in circumstances of enormous vulnerability, perceived as individuals in their suffering. Much has been done in this field in the majority of EU countries. A great deal remains to be done.

Palliative care can only be developed if volunteers will come forward for this mission, offering their time and their capacities for listening. Healthcare professionals are also needed, those ready to devote a major part of their career to this mission, which is both enriching but also stressful because of the daily confrontation with the reality of the finitude of human life. To encourage their recruitment in sufficient numbers, it is necessary that the greatness of this task should be recognised and valued, especially in the media, and that political decision-makers should have the courage to commit to this idea and take the necessary decisions.

⁷⁶ Cf. Chris Gastmans, Dignity-Enhancing Nursing care, A Foundational Ethical Framework, *Nursing Ethics*, 2013, Vol. 20, Nr 2, pp. 142-149.

LIST OF MEMBERS OF THE WORKING GROUP ON ETHICS IN RESEARCH AND MEDICINE

1. Matthias Beck - Austria
2. Carlo Bellieni - Italy
3. Franz-Josef Bormann - Germany
4. Jan Dacok - Slovakia
5. Patrick Daly - General Secretary of COMECE
6. Elisa Garcia - The Netherlands
7. Pál Ottó Harsányi - Hungary
8. David A. Jones - England and Wales
9. George Joseph - Scandinavia
10. Georgi Jovchev - Bulgaria
11. Jonas Juškevičius - Lithuania
12. Agustín Losada - Spain
13. Marian Machinek - Poland
14. Ioan Mitrofan - Romania
15. Marie Therese Rainey - Ireland
16. José Ramos-Ascensão - Legal advisor
for Health, Research & Bioethics at COMECE
17. Patrick Verspieren - France
18. Tadej Strehovec - Slovenia
19. Marek Vácha - Czech Republic
20. Bert Vanderhaegen - Belgium
21. Ray Zammit - Malta



