HUMAN RIGHTS, DIGNITY AND END-OF-LIFE SITUATIONS

Selected adopted texts

COUNCIL OF EUROPE
CONSEIL DE L'EUROPE

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Content

Preface

It is often said that the Council of Europe is the organisation which puts citizens' interests first and those of governments only second. Indeed, inhabitants of its member states can rely on a number of fundamental decisions of the Council of Europe and its organs to help them face the challenges of daily life.

Many of these decisions are binding on member states, like the European Convention on Human Rights of 1950, borne out of the horrendous experiences of massive human rights and human dignity violations during World War Two; or the Oviedo Convention of 1987 which addresses fast-paced biological and medical progress and its repercussions on fundamental rights, to name just two of the numerous Council of Europe agreements. Moreover, the Organisation has issued a great number of recommendations which, while not legally binding, have far-reaching political impact.

This brochure brings together key Council of Europe guidelines on one of the most important subjects faced by human beings – that is to say, coping with the issue of passing away. As with any challenging situation, help is needed both from individuals and from society in general – and this is all the more the case for those who are terminally ill.

The Parliamentary Assembly of the Council of Europe (PACE) adopted, with an overwhelming majority, the Recommendation on the protection of the human rights and dignity of the terminally ill and dying (Recommendation 1418) in 1999. The Committee of Ministers welcomed this text, and several judgments of the European Court of Human Rights have drawn upon it. In 2009, a PACE Resolution on palliative care, and in 2014, the Guide on the decision-making process regarding medical treatment in end-of-life situations, followed.

We do hope that the Council of Europe documents compiled here will be useful for citizens concerned with and affected by such important questions. We also hope that the texts can provide guidance to decision makers in regulating these crucial societal issues, with the aim that humanity and humane be forever synonymous.

Prof. Günter Virt Scientific Adviser Recommendation 1418 (1999)	Edeltraud Gatterer Rapporteur Recommendation 1418 (1999)	Gerhard Jandl Permanent Representative of Austria to the Council of Europe

1. Protection of the human rights and dignity of the terminally ill and the dying Recommendation 1418 (1999)[1]

Parliamentary Assembly

1. The vocation of the Council of Europe is to protect the dignity of all human beings and the rights which stem therefrom.

2. Medical progress, which now makes it possible to cure many previously incurable or fatal diseases, the improvement of medical techniques and the development of resuscitation techniques, which make it possible to prolong a person's survival, to defer the moment of death. As a result the quality of life of the dying is often neglected, and their loneliness and suffering ignored, as is that of their families and care-givers.

3. In 1976, in its Resolution 613, the Assembly declared that it was "convinced that what dying patients most want is to die in peace and dignity, if possible with the comfort and support of their family and friends", and added in its Recommendation 779 (1976) that "the prolongation of life should not in itself constitute the exclusive aim of medical practice, which must be concerned equally with the relief of suffering".

4. Since then, the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine has formed important principles and paved the way without explicitly referring to the specific requirements of the terminally ill or dying.

5. The obligation to respect and to protect the dignity of a terminally ill or dying person derives from the inviolability of human dignity in all stages of life. This respect and protection find their expression in the provision of an appropriate environment, enabling a human being to die in dignity.

6. This task has to be carried out especially for the benefit of the most vulnerable members of society, a fact demonstrated by the many experiences of suffering in the past and the present. Just as a human being begins his or her life in weakness and dependency, he or she needs protection and support when dying.

7. Fundamental rights deriving from the dignity of the terminally ill or dying person are threatened today by a variety of factors:

7.1. insufficient access to palliative care and good pain management;

7.2. often lacking treatment of physical suffering and a failure to take into account psychological, social and spiritual needs;

[1] Assembly debate on 25 June 1999 (24th Sitting) (see Doc. 8421, report of the Social, Health and Family Affairs Committee, rapporteur: Mrs Gatterer; and Doc. 8454, opinion of the Committee on Legal Affairs and Human Rights, rapporteur: Mr McNamara). Text adopted by the Assembly on 25 June 1999 (24th Sitting).

7.3. artificial prolongation of the dying process by either using disproportionate medical measures or by continuing treatment without a patient's consent;

7.4. the lack of continuing education and psychological support for health-care professionals working in palliative medicine;

7.5. insufficient care and support for relatives and friends of terminally ill or dying patients, which otherwise could alleviate human suffering in its various dimensions;

7.6. patients' fear of losing their autonomy and becoming a burden to, and totally dependent upon, their relatives or institutions;

7.7. the lack or inadequacy of a social as well as institutional environment in which someone may take leave of his or her relatives and friends peacefully;

7.8. insufficient allocation of funds and resources for the care and support of the terminally ill or dying;

7.9. the social discrimination inherent in weakness, dying and death.

8. The Assembly calls upon member states to provide in domestic law the necessary legal and social protection against these specific dangers and fears which a terminally ill or dying person may be faced with in domestic law, and in particular against:

8.1. dying exposed to unbearable symptoms (for example, pain, suffocation, etc.);

8.2. prolongation of the dying process of a terminally ill or dying person against his or her will;

8.3. dying alone and neglected;

8.4. dying under the fear of being a social burden;

8.5. limitation of life-sustaining treatment due to economic reasons;

8.6. insufficient provision of funds and resources for adequate supportive care of the terminally ill or dying.

9. The Assembly therefore recommends that the Committee of Ministers encourage the member states of the Council of Europe to respect and protect the dignity of terminally ill or dying persons in all respects:

a. by recognising and protecting a terminally ill or dying person's right to comprehensive palliative care, while taking the necessary measures:

1. to ensure that palliative care is recognised as a legal entitlement of the individual in all member states;

2. to provide equitable access to appropriate palliative care for all terminally ill or dying persons;

3. to ensure that relatives and friends are encouraged to accompany the terminally ill or dying and are professionally supported in their endeavours. If family and/or private networks prove to be either insufficient or overstretched, alternative or supplementary forms of professional medical care are to be provided;

4. to provide for ambulant hospice teams and networks, to ensure that palliative care is available at home, wherever ambulant care for the terminally ill or dying may be feasible;

5. to ensure co-operation between all those involved in the care of a terminally ill or dying person;

6. to ensure the development and implementation of quality standards for the care of the terminally ill or dying;

7. to ensure that, unless the patient chooses otherwise, a terminally ill or dying person will receive adequate pain relief and palliative care, even if this treatment as a side-effect may contribute to the shortening of the individual's life;

8. to ensure that health professionals are trained and guided to provide medical, nursing and psychological care for any terminally ill or dying person in co-ordinated teamwork, according to the highest standards possible;

9. to set up and further develop centres of research, teaching and training in the fields of palliative medicine and care as well as in interdisciplinary thanatology;

10. to ensure that specialised palliative care units as well as hospices are established at least in larger hospitals, from which palliative medicine and care can evolve as an integral part of any medical treatment;

11. to ensure that palliative medicine and care are firmly established in public awareness as an important goal of medicine;

b. by protecting the terminally ill or dying person's right to self-determination, while taking the necessary measures:

1. to give effect to a terminally ill or dying person's right to truthful and comprehensive, yet compassionately delivered information on his or her health condition while respecting an individual's wish not to be informed;

2. to enable any terminally ill or dying person to consult doctors other than his or her usual doctor;

3. to ensure that no terminally ill or dying person is treated against his or her will while ensuring that he or she is neither influenced nor pressured by another person. Furthermore, safeguards are to be envisaged to ensure that their wishes are not formed under economic pressure;

4. to ensure that a currently incapacitated terminally ill or dying person's advance directive or living will refusing specific medical treatments is observed. Furthermore, to ensure that criteria of validity as to the scope of instructions given in advance, as well as the nomination of proxies and the extent of their authority are defined; and to ensure that surrogate decisions by proxies based on advance personal statements of will or assumptions of will are only to be taken if the will of the person concerned has not been expressed directly in the situation or if there is no recognisable will. In this context, there must always be a clear connection to statements that were made by the person in question close in time to the decision-making situation, more precisely at the time when he or she is dying, and in an appropriate situation without exertion of pressure or mental disability. To ensure that surrogate decisions that rely on general value judgements present in society should not be admissible and that, in case of doubt, the decision must always be for life and the prolongation of life;

5. to ensure that – notwithstanding the physician's ultimate therapeutic responsibility – the expressed wishes of a terminally ill or dying person with regard to particular forms of treatment are taken into account, provided they do not violate human dignity;

6. to ensure that in situations where an advance directive or living will does not exist, the patient's right to life is not infringed upon. A catalogue of treatments which under no condition may be withheld or withdrawn is to be defined;

c. by upholding the prohibition against intentionally taking the life of terminally ill or dying persons, while:

1. recognising that the right to life, especially with regard to a terminally ill or dying person, is guaranteed by the member states, in accordance with Article 2 of the European Convention on Human Rights which states that "no one shall be deprived of his life intentionally";

2. recognising that a terminally ill or dying person's wish to die never constitutes any legal claim to die at the hand of another person;

3. recognising that a terminally ill or dying person's wish to die cannot of itself constitute a legal justification to carry out actions intended to bring about death.

2. Protection of the human rights and dignity of the terminally ill and the dying
Report of the Social, Health and Family Affairs Committee of the Parliamentary Assembly, 21 May 1999 (Doc. 8421)

Rapporteur: Mrs Edeltraud Gatterer, Austria, Group of the European People's Party

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Summary

At the approach of death, patients are faced with specific fears, anxieties and dangers, which are most often ignored or underestimated. Their vulnerability, state of weakness and dependency, their suffering and loneliness are painful factors which weigh heavily on them.

Respect and protection of the dignity of a terminally-ill or a dying person implies above all the provision of an appropriate environment, enabling him or her to die in dignity. Priority should therefore be given to the development of palliative care and the treatment of pain, and to the social and psychological support of patients and their families.

Legal and social protection should be strengthened. In this framework, a right to self-determination and a right to comprehensive information, need to be recognised for the terminally-ill and the dying. Patients should never be given treatment against their will.

Lastly, the fundamental right to life as established in Article 2 of the European Convention on Human Rights needs to be recalled and fully guaranteed, in the special conditions which constitute the terminal phase of life. The report consequently calls on states to uphold the prohibition of intentionally taking the life of terminally-ill or dying persons.

I. Draft recommendation [see part 1, adopted recommendation]

II. Explanatory memorandum by Mrs Gatterer

Introduction

1. It is undisputed that dealing with the concerns of the terminally ill or dying is to be guided by the notion of human dignity and the concept of human rights founded therein.

2. The 1997 European Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine protects in accordance with other relevant international documents on human rights the dignity and identity of every human being. It guarantees everybody, without discrimination, respect for their integrity and rights and fundamental freedoms.

3. Dignity is bestowed equally upon all human beings, regardless of age, race, sex, particularities or abilities, of conditions or situations, which secures the equality and universality of human rights. Dignity is a consequence of being human. Thus a condition of being can by no means afford a human being its dignity nor can it ever deprive him or her of it.

4. Dignity is inherent in the existence of a human being. If human beings possessed it due to particularities, abilities or conditions, dignity would neither be equally nor universally bestowed upon all human beings. Thus a human being possesses dignity throughout the course of life. Pain, suffering or weakness do not deprive a human being of his or her dignity.

5. The equality and universality of human dignity and human rights do not originate from a convention. One possesses dignity and its subsequent rights not due to the recognition of other human beings, but due to one's descent from them.

6. An individual's dignity can be respected or violated, yet it can neither be granted nor lost. Respect for human dignity is independent of factual reciprocity. Respect for human dignity is also due where reciprocity is not, not yet or not anymore possible (i.e. towards patients in coma). To believe that human dignity may be divided or limited only to certain stages or conditions of life is a form of disregard for human dignity.

7. The recognition and protection of the dignity of the most vulnerable members of society – who may find it difficult to express themselves on a societal level – have proven to be inadequate. The terminally ill or dying are among these vulnerable members of society. Due to their public marginalisation they are in danger of being exposed to individual, social and societal pressure.

8. The responsibility of affording a terminally ill or dying person with the means and the infrastructure worthy of his or her dignity results from the fundamental understanding that human dignity is imperishable.

9. Among the factors obstructing humane dying and palliative care in our societies, the primary one is the decreasing willingness to confront oneself with death and dying.

10. Most people wish to die in familiar surroundings, yet, in Europe, in the majority of cases, death takes place in hospitals and nursing homes. This is related to lacking or deficient social structures.

11. Although palliative medicine and care have made remarkable progress, its practical application still appears far behind the state of the art. This deficiency results from lack of training and teaching, false apprehensions, prejudices as well as lack of societal awareness.

12. It is evident that there is a tendency to use excessive technical therapy and to apply inappropriately high medical technology even in cases where an agonising process of dying thereby is prolonged in an inhumane way.

13. Especially deficiencies in the structures of public health care providers create problems with regard to care for the terminally ill or dying.

14. Human care for the terminally ill or dying implies the readiness to provide sufficient allocations of funds and resources for the benefit of palliative medicine and care.

15. Illness, suffering and death per se cannot deprive any individual of his or her dignity, yet often, certain circumstances may be regarded as inhumane to the extent that an individual is left alone in his helplessness in those instances where suffering could be avoided.

16. Meeting the needs of a terminally ill or dying person is the purpose of palliative medicine and care. Palliative medicine and care therefore should become an integral part of medicine as such.

17. The World Heath Organisation describes palliative care as "the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms and of psychological, social and spiritual problems is paramount. The goal of the palliative care is achievement of the best possible quality of life for patients and their families."

18. Palliative medicine and care thus is an approach of understanding human being holistically in both its psychological and physical dimensions. In addition to pain-treatment in the narrower sense of the word, it therefore comprises psycho-social and spiritual care.

19. An individual's right to self-determination is rooted in his inviolable and inseparable dignity. This right to self-determination is to be protected against any extraneous influences.

20. The legal systems of the Member States of the Council of Europe penalise the killing of human beings. Now, it is necessary to confirm this fundamental legal good especially with regard to the terminally ill and dying, since there is a grave danger that in particular with regard to this group of people at their last stage of life, justifications may be sought under various pretences (pity, shortage of resources, ambivalent expressions of will) in order to undermine the fundamental prohibition against taking life.

A. To recognise and to protect a terminally ill or dying person's right to comprehensive palliative care

21. The Member States are to pay special attention to making it possible to fulfil the wish of the majority of the terminally ill or dying to be able to die in a familiar surrounding. Ambulatory, flexible care services are to be supported. Socio-political programmes operating under given conditions are to enable children to accompany their parents in taking leave of this world as they themselves cared for their children when they entered into it.

22. Apart from the Convention for the Protection of Human Rights and the Dignity of the Human Being with Regard to the Application of Biology and Medicine, article 13 of the European Social Charter also foresees equal access to health care services of appropriate quality. To guarantee this principle for the terminally ill or dying is a pressing need.

23. One important political goal of health services is to guarantee palliative medicine and care of appropriate quality. The humanity of a society finds its expression not least in its care of the weak and dying.

24. If a family desires to care for a dying person they often need professional advice and help. There is not only a need for medical and nursing assistance but also for psychological and, if wished, for religious and spiritual support. Familiar relations in the widest sense (family, friends, neighbours ...) as close and trusted contacts, are to be supported by professional services in such a way that they can adequately accompany the last phase of life at home. In this context the necessary measures must be taken to provide for instruction in basic care for this circle of persons.

25. The additional use of voluntary assistants play an important part in accompanying and caring for dying persons. Continuity and normality of life can be maintained through their contribution. Volunteers in the care of dying persons should be trained and supported and take over independent tasks in a team with professionals.

26. In numerous hospitals throughout Europe, relatives and friends or other involved persons are restrained from spending the amount of time they would wish to spend with a terminally ill or dying. Adequate infrastructures are thus to be provided enabling and enhancing the prudent inclusion of the familiar environment of a terminally ill or dying person, whose wishes are thereby to be given prevalence.

27. The goal of palliative medicine and care is to provide a comprehensive improvement in the quality of life of the patient while respecting his or her wishes. A necessary precondition in achieving this goal is the mutually trusting co-operation of all persons involved.

28. The goal of medical intervention is to cure illness and relieve pain, not however to prolong life at all costs. To relieve all suffering of persons who – at least by human standards – must be deemed terminally ill is one of a physician's obligations. The unbearable symptoms and pain of a patient should not be left untreated for fear of a minimal shortening of the life span which might be related to the therapy for the alleviation of pain. This fear is often the cause of inadequate efforts to relieve pain. In these difficult instances physicians are to be granted adequate discretionary powers.

29. Administrative barriers to providing an efficient pain relief treatment are to be removed.

30. All professions confronted with terminally ill or dying persons are to receive qualified instructions in the course of their duties. Forms of education and further training are to be preferred that are interdisciplinary and include – in addition to the medical or nursing fields – relevant aspects from psychology, sociology, anthropology, ethics or theology in order to be able to accept and respect persons in the last phase of life. Therefore, the education of physicians, nurses and other health professionals in all Member States of the European Council concerning palliative medicine and care has to be improved.

31. The degree of recognition of palliative medicine and care varies considerably throughout Europe. If there are still no or only inadequate educational facilities for palliative medicine and care no efforts should be spared in coming abreast with the state of the art. Palliative medicine and care as a discipline should be prominent in the programme of every educational institution for future health professionals. Graduates of these schools and universities should have successfully completed practical and theoretical examinations in the field of palliative medicine and care.

32. Since 1967, when the physician and social worker Cicely Saunders founded the modern hospice in England, there have been exemplary cases of adequate pain relief through the observant control of symptoms and attentive humane care that testify to the fact that it is possible to make the last phase of life worth living and to maintain human dignity: The hospice movement has spread – with varying density – throughout Europe as a grass-root movement. In contrast to the traditional hospital the hospice focuses its attention on the dying person in companionship with his or her closest relations. Supporting the foundation of further hospices

is one effective way to provide for the care of the terminally ill or dying in accordance with human dignity.

33. A sufficient number of hospital wards and hospices must be established in order to make possible the education and further education in palliative medicine and care. Palliative medicine and care – as is the case with other fields as well - cannot be learned merely theoretically. Every student of medicine or nursing should be obliged to absolve a clinical practice in a ward dealing mainly with palliative medicine and care. This applies equally to the postgraduate training for physicians, psychologists, psychotherapists as well as social workers. These professions must learn that accompanying the terminally ill or dying can only be accomplished in an interdisciplinary team. As medical progress cannot exclude the care for the terminally ill and dying provisions must be made for research in the field of palliative medicine and care. For this reason as well it is necessary to establish further palliative wards and hospices.

34. Whenever killings of the terminally ill or dying in institutions have shaken the general public – as was the case in Austria, Germany, Denmark, the Netherlands, France and other countries – deficiencies in training and counselling and coaching of the responsible health care staff have regularly shown to be one of the main reasons for these incidents. This demonstrates that professional as well as voluntary health care staff are in need of support to fulfil their task. Support is to be provided in part by the interdisciplinary team (this needs sufficient time and space) and in part by staff counsellors and coaches.

35. Deficiencies in their training as well as the feeling of being overwhelmed by their task may mislead health care staff to contemplate taking the live of a terminally ill or dying person. The wish to die expressed by a terminally ill or dying person should therefore be thoroughly examined. Health care staff as well as the individual's family, friends or other involved persons are primarily obliged to determine whether this wish is the authentic expression of the individuals determination or rather a cry for more intensive therapeutic, social and spiritual attention.

36. The aims of this training should meet the following standards:

- palliative medicine and care affirm life and regard dying as a normal process,
- neither hastens nor postpones death,
- provides relief from pain and other distressing symptoms,
- integrates the psychological and spiritual aspects of patient care,
- offers a support system to help patients live as actively as possible until death, and
- offers a support system to help the family and other involved persons cope during the patient's illness in their own bereavement.

37. Research on palliative medicine and care is urgently needed. It should address the physical, psychological and socio-economic issues related to caring for people with terminal illnesses. Such research should address pain and other physical symptoms, depression and other mental health conditions, spirituality and existential meaning, communication between

physician and patient, family and other involved persons, burdens on care-givers and economic hardships.

38. In the public discourse it is important to stress that palliative medicine and care need to become and stay an integral part of any medical teaching and training. Any medical therapy should comprise palliative components, palliative medicine and care, however, should not be implemented in isolation.

B. To protect a terminally ill or dying person's right to self-determination

39. According to article 5 of the Convention on the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine any medical intervention is allowed only after the person in question has been fully informed about the projected intervention and has freely agreed to it. This is also the case with the terminally ill and dying.

40. Modern medical diagnosis and therapy can ease much pain and suffering when they are applied carefully and in accordance with the will of the individual in question. The medically possible does not, however, always correspond with the wishes of the terminally ill or dying person. The patient must be given the real – not the only theoretical – opportunity to refuse further therapy. However, in order to be able to participate meaningfully in the decision making, full information – about the illness itself, the assumed prognosis and the sense and objectives, the burdens and the goals of further diagnostic and therapeutic efforts – must be made comprehensible to the patient.

41. It is not unusual that fulfilling the basic rights of each person to all available information about his or her health condition presents difficulties. Most recent studies show that a significant number of physicians hesitate to provide comprehensible information with reference to diagnosis and further treatment. These explanations are often considered to be the most difficult and burdensome professional task because they are concerned not only with empathetically communicating medical information but also with providing help in making life-and-death decisions. Given the patients consent, his or her family or other involved persons should ideally be included in such consultations. In the interest of his or her self-determination, a terminally ill or dying person needs careful attention as the questions and anxieties with which he or she is concerned in this final phase of life.

42. A terminally ill or dying person can make a self-determined decision for or against a further life prolonging treatment only on the basis of truthful and comprehensible information as to his or her condition. Foregoing therapy instead of unwanted prolongation of suffering – when this is in accord with the wish of the patient – must be acceptable and legally guaranteed. The knowledge that a cessation of therapy can be legal and is strictly to be distinguished from "physician-assisted suicide" or "mercy killing" must be conveyed to professionals in the field of health.

43. Any pressure on the terminally ill or dying to forego therapy for economic reasons must be avoided. It has been empirically demonstrated, that the health costs in the last phase of life rise considerably. In view of the scarcity of funds and resources of both the health sector and, within that sector, for palliative medicine and care, there is a grave danger that instead of dignified support of a terminally ill or dying person economic pressure makes itself felt to forego further – and arguably appropriate – curative or palliative therapy.

44. While expressions of the will of a patient to forego certain treatments must be recognised and abided to by the physician, the wish for actively ending life must be denied. The physician must never impinge on the integrity of the body or soul of a patient even upon his or her wish.

45. The wishes of a terminally ill or dying person, the fulfilment of which is contrary to human dignity as well as relevant codes of professional conduct carry no weight. Article 4 of the Convention for the Protection of the Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine demands the observance of relevant codes of professional conduct (e.g. the World Medical Association Declarations of Madrid - 1987 and Marbella - 1992). Wishes of a terminally ill or dying person that are not in line with these codes of professional conduct are not to be executed. The following passage from the Madrid World Medical Association Declaration of 1987 maintains: "deliberately ending the life of a patient, even at the patient's own request or at the request of close relatives, is unethical. This does not prevent the physician from respecting the desire of a patient to allow the natural process of death to follow its course in the terminal phase of sickness."

46. Wishes such as those for "mercy killing" and "assisted suicide" are those that are illegitimately put to health care professionals. Such wishes are not to be executed, as they are in violation of ethically founded codes of professional conduct. The World Medical Association Marbella Declaration of 1992 maintains: "Physician-assisted suicide, ..., is unethical and must be condemned by the medical profession."

47. In order to preserve the right to self determination of those terminally ill or dying persons who are temporarily or permanently incapacitated, formerly expressed wishes regarding medical care should be taken into serious consideration. This conforms to article 9 of the Convention for the Protection of the Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine.

48. In the consideration of anticipated wishes and statements it must be distinguished between a refusal of treatment and other wishes regarding for example a specific treatment.

49. Wishes for a specific treatment, however, must be viewed from the standpoint of medical advisability, because a patient cannot expect a physician to initiate a treatment that does not conform to the standards of his or her profession. A patient cannot force a physician to undertake a treatment contrary to the rules of medical science or the ethics of the medical profession. Should a physician on the basis of his or her professional competence be convinced that it is necessary to act contrary to a written wish of a patient, then he or she should make a written explanation to clarify the decision for the patient, the patient's attorney, and his or her family.

50. In cases in which – due to factual incapacitation of the terminally ill or dying person – a surrogate decision becomes necessary this decision is to be taken to the patients welfare. Determination of the patients welfare is to be undertaken in a process of deliberation between those involved in the individual's care. Proxies, family or other involved persons may play an important part in this process. They should, however, remain simply interpreters and refrain from making independent value judgements. Their role in the decision making process must remain a subsidiary one which is overridden as soon as the patient decides him- or herself or as

soon as the physician gains the impression that the views of the family are not in the interests of the dying person but are guided by extraneous interests.

51. Criteria of validity as to the bearing of such surrogate or proxy decisions are of particular relevance with reference to permanently incapacitated (e.g. permanently incapacitated persons such as the mentally disabled). For the protection of this particularly vulnerable group it appears essential to determine certain treatments that under no conditions may be withheld or withdrawn.

C. To uphold the prohibition against intentionally taking life also with regard to terminally ill or dying persons

52. The European Convention for Protection of Human Rights and Fundamental Freedoms states in article 2 that "everyone's right to life shall be protected by law. No one shall be deprived of his life intentionally...".

53. The fundamental right to life and the prohibition of intentionally taking human life are to be upheld also under the special conditions of the terminal phase of an individual's life. Dying is a phase of life. Thus the right to die in dignity corresponds with the right to a life in dignity. This principle of an unconditional protection of dignity is also reflected in the preamble of the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: "Convinced of the need to respect the human being both as an individual and as a member of the human species and recognising the importance of ensuring the dignity of the human being".

54. Guaranteeing the individual's right to a life in dignity the Member States thereby acknowledge a right to die in dignity. A terminally ill or dying person has the right to self-determination as to the course of the process of dying, he or she, however, has no right to be killed.

55. The legal system prohibits the killing of a human being even if the killing is wished for by the individual. This applies to the elderly, the sick or the disabled and indisputable to the terminally ill or dying as well. Abating the prohibition to take a human being's life with regard to the terminally ill or dying will bring incalculable consequences for the legal system. Inevitably individual or societal pressure on a terminally ill or dying person would mount, given that he or she is under the impression of being a burden while society offers the option of having oneself killed. Experiences in societies that have a lenient approach towards the prohibition against taking life show that in due consequence human beings are killed without their consent. This development undermines the fundamental protection of life and furthermore threatens to lead to the acceptance of annihilation of life deemed senseless.

56. Society recognises the practice and especially the ethics of the healing professions that nobody shall participate in the taking of the life of another human being.

57. A terminally ill or dying person's wish to die constitutes no legal justification to have one's life taken by another human being. Otherwise this would mean that the legal system would signal permission to kill another human being deliberately and actively.

58. Taking a patient's life is no therapeutic option, especially as it is not directed towards terminating the patients suffering but rather at terminating the patient himself.

59. With no claim to being complete this recommendation strives to promote measures for the protection of terminally ill or dying. The Council of Europe remains truthful towards its intention and ambition of protecting human rights with special awareness of the needs of the most vulnerable and weak members of society. Amongst the weakest members of society are the terminally ill or dying.

Reporting committee: Social, Health and Family Affairs Committee
Budgetary implications: none
Reference to committee: Doc. 7236, Reference No. 1996, 15.03.95
Draft recommendation adopted by the committee on 11 May 1999 with 19 votes in favour, 4 against and 4 abstentions
Members of the committee: *Mr Cox* (Chairman), Mr Weyts, *Mrs Ragnarsdottir*, *Mr Gross* (Vice-Chairs), Mrs Albrink, *MM. Alis Font, Arnau*, *Mrs Belohorska*, Mrs Biga-Friganovic, Mrs Björnemalm, *Mrs Böhmer*, MM. Christodoulides, *Chyzh, Dees*, Dhaille, *Duivesteijn*, Evin, *Flynn*, *Mrs Gatterer*, *MM. Gibula, Gregory*, Gusenbauer, Haack, *Hancock, Hegyi*, *Mrs Høegh*, Mrs Hornikova, Mrs Jirousova, Mr Kalos, Mrs Kulbaka, Mrs Laternser, *Mr Liiv, Mrs Lotz*, Mrs Luhtanen, Mr Lupu (Alternate: *Mr Popescu*), Mrs Markovska, MM. Marmazov, Martelli (Alternate: *Mr Evangelisti*), *Mattéi*, Mozgan, Mularoni, Mrs Näslund, MM. Niza, Paegle, *Poças Santos*, Mrs Poptodorova, *Mrs Pozza Tasca, Mrs Pulgar, MM. Raskinis*, Regenwetter, Rizzi (Alternate: *Mr Polenta*), *Sharapov*, Silay, Sincai (Alternate: *Mr Paslaru*), Skoularikis, Mrs Stefani, MM. Surján (Alternate: *Mr Kelemen*), Tahir, Valkeniers, Vella, Mrs Vermot-Mangold, MM. Volodin, Voronin, *Wójcik*, Yürür
NB: The names of those members present at the meeting are printed in italics.
Secretaries to the committee: Mr Perin, Mrs Meunier and Mrs Clamer

3. Palliative care: a model for innovative health and social policies
Resolution 1649 (2009)[2]

Parliamentary Assembly

1. The Parliamentary Assembly notes that palliative care is a substantial and socially innovative addition to curative, highly scientific medicine, where the subjective well-being of the patient comes after the goal of curing an illness and which involves therapy-related restrictions and sometimes massive side effects.

2. In this connection, the Assembly builds its position on the 2002 World Heath Organization (WHO) definition: 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.

3. The Assembly nevertheless underlines that the innovative potential of the approach is not given sufficient emphasis in this definition, which could lead public opinion to believe that palliative care is a humanitarian luxury which we can no longer afford in the current difficult economic situation.

4. The Assembly notes that, especially in the final stages of life and in spite of the high standards and huge costs involved, contemporary medical care fails to meet the basic needs of many people (seriously ill, chronically ill, patients requiring high levels of individual care). Against the background of the increasing domination of health and social policies by economics, growing numbers of people do not have a strong enough lobby to defend their basic rights.

5. The Assembly regards palliative care as a model for innovative health and social policies, as it takes account of the changes in our perceptions of health and illness and does not assume that curing diseases is the precondition for self-determination and participation in society. Autonomy is accordingly the requirement for a subjective form of "health", which includes people's freedom to decide for themselves how to deal with illness and death.

6. The Assembly notes that palliative care enables people who have serious illnesses, are suffering pain or are in a state of great despair, to exercise self-determination. The approach is not, therefore, just based on need, but contributes directly to human, civic and participation rights being asserted right up to death.

7. The Assembly believes that there is an urgent need to extend the scope of this innovative treatment and care method. In addition to the terminally ill, palliative care should be available to the seriously ill and chronically ill and all those requiring high levels of individual care who may benefit from the approach.

[2] Assembly debate on 28 January 2009 (6th Sitting) (see Doc. 11758, report of the Social, Health and Family Affairs Committee, rapporteur: Mr Wodarg). Text adopted by the Assembly on 28 January 2009 (6th Sitting).

8. Palliative care can be seen as an approach to an appropriate type of care developed on a practical level, which involves patient-oriented integration of medicine and care, as well as the provision of other healthrelated services and social resources. For instance, this includes the successful involvement of voluntary helpers and the possibility of including social, psychological and spiritual support if necessary. This can be more important for individual patients than medical care in the stricter sense.

9. With the above, the Assembly also draws conclusions from the debate on the subject of euthanasia, which showed that liberal constitutional states cannot leave ethical questions concerning the life and death of individuals unanswered.

10. Sticking to ethical pluralism does not ensure maximum individual freedom in ethical issues, but, in society it gives precedence to randomness, relativism and practical nihilism over properly founded ethical positions. This results in general disorientation and ultimately in the erosion of the liberal constitutional state.

11. In this connection, the Assembly refers to the relevant recommendations on dealing with the terminally ill as set out in the European Health Committee's report (1980) "Problems related to death: care for the dying" and in its Recommendation 1418 (1999) on protection of the human rights and dignity of the terminally ill and the dying.

12. It recognises that the limits of any medical intervention are determined by the autonomy of the individual patients in so far as they express their will not to receive curative treatment or, regardless of any medical assessment of their state of health, have done so explicitly in a living will, for instance.

13. The Assembly hopes that palliative care also offers individuals who have given up hope the prospect of dying in dignity if they are allowed to turn down curative medicine but accept pain relief and social support.

14. It therefore regards palliative care as an essential component of appropriate health care based on a humane concept of human dignity, autonomy, human rights, civic rights, patient rights and a generally acknowledged perception of solidarity and social cohesion.

15. It underlines that Recommendation Rec(2003)24 of the Committee of Ministers to member states on the organisation of palliative care already provides a good basis for strengthening the palliative care approach.

16. The Assembly endorses the four applications of palliative care listed in Recommendation Rec(2003)24 following the WHO definition – namely symptom control; psychological, spiritual and emotional support; support for the family; and bereavement support – and accordingly, specifically recommends that member states:

16.1. establish a consistent and comprehensive health-policy approach to palliative care at national level;

16.2. promote international co-operation between the various organisations, institutions, research institutes and other players in the palliative care movement.

17. In view of the great differences in developments in this area in the various countries in Europe, the Assembly is aware that, although rapid implementation in existing health-care structures is desirable with a view to sustainable funding arrangements, the funding arrangements themselves may involve serious obstacles for such a flexible care and treatment approach.

18. It therefore believes there is a need for detailed analysis of structural obstacles and accurate analysis of needs on the basis of a minimum data set of the kind called for in the appendix to Recommendation Rec(2003)24 in order to achieve sustainable, effective changes in existing health systems.

19. It notes that wide-ranging discussion in society on the priorities of health care based on sensible health objectives is necessary if fundamental rights are to take precedence over further patient rights in the health system. As the protection of fundamental rights is a government task, this must not be left to pressure group politics.

20. The Assembly believes that ethics therefore have a fundamental role to play as a practical philosophy in shaping the discussion of health objectives and care priorities in society.

21. Therefore, with regard to general recommendations, the Assembly recommends that member states:

21.1. focus on ethics not only in application issues but as a matter of principle, as only the clarification and typological classification of fundamental positions will enable a stable consensus to be reached in society about controversial ethical issues and a fair allocation of resources;

21.2. seek to ensure improved rewards for non-product-related services both in health and in economic and financial policies so that social policy can draw on economic policy and fiscal incentives and to counter more effectively the increasing domination of society by economics;

21.3. in general, seek to strengthen primary health care so as to protect patients against inappropriate medical intervention and place greater emphasis again on the importance of communication between doctor and patient as the basis for rational, patient-oriented medicine;

21.4. given governments' capacity for influence, promote an approach to medicine in society which highlights palliative care as a key pillar of care provision to which patients are entitled.

22. Moreover, with regard to practical recommendations, the Assembly recommends that member states:

22.1. consider effective symptom control for seriously ill patients as a key requirement for the doctorpatient relationship and patient self-determination and promote this view, thereby also bringing the innovative potential of the palliative care method into the domain of curative medicine;

22.2. within a consistent health-policy approach for the specific strategy of improving palliative healthcare provision, identify practical indicators that can be used to check what progress has been made in patient care over a given period;

22.3. draw up annual reports so that shortcomings can be analysed as quickly as possible and dealt with appropriately;

22.4. react promptly, for instance through special arrangements for the funding of palliative care, if it becomes apparent that the appropriate use of painkillers is not taking place as desired or the standardisation of hospital treatment (through diagnosis-related groups − DRGs) is having a negative impact on existing structures and practices;

22.5. with regard to legal regulations on living wills:

22.5.1. avoid creating legal arrangements which could lead to interpretation problems in practice;

22.5.2. conduct a comprehensive assessment of the legal consequences, taking account of possible legal side effects such as asset liability ("care as a financial loss").

4. Palliative care: a model for innovative health and social policies
Report of the Social, Health and Family Affairs Committee, 4 November 2008 (Doc. 11758) (Summary)[3]

Rapporteur: Mr Wolfgang Wodarg, Germany

Summary

The importance of palliative care as a comprehensive approach, with the potential to complete and improve existing care programmes, is now recognised in many of the Council of Europe's member states. Palliative care is a substantial and socially innovative addition to curative, highly scientific medicine, where subjective well-being of the patient comes after the goal of curing an illness and which involves therapy-related restrictions and sometimes massive side-effects.

The report endeavours to highlight the central problem of the highly sophisticated and costly health care provided particularly in western Europe, which, at ever shorter intervals, produces new medical techniques and medicines, raising high public expectations of curative success. At the same time, however, this type of health care is increasingly – and obviously – failing to meet the basic needs of people suffering from chronic or rare diseases.

The rapporteur considers palliative care as a model for innovative health and social policies. Palliative care does not simply meet a cultural and humanitarian need of the most pressing kind. It also provides an innovative structure which, if intelligently developed, will not only produce sustainable change in the health sector, but may also serve as a recipe for success in other policy areas with serious, systemic and recurrent problems (for example, drug prevention).

The rapporteur therefore regards palliative care as an essential component of appropriate health care based on a humane concept of human dignity, autonomy, human rights, patient rights and a generally acknowledged perception of solidarity and social cohesion.

The report advocates a wide-ranging discussion in society on the priorities of health care based on sensible health objectives and on the fundamental rights of the patients. These objectives must not be left to competition between lobby groups, as the protection of fundamental rights is a government task and not a matter for pressure group politics.

[3] Full report available at http://assembly.coe.int/nw/xml/XRef/Xref-XML2HTML-en.asp?fileid=12060&lang=en.

APPENDIX

Guide on the decision-making process regarding medical treatment in end-of-life situations (2014)

Contents

Foreword

This guide was drawn up by the Committee on Bioethics (DH-BIO)[4] of the Council of Europe in the course of its work on patients' rights and with the intention of facilitating the implementation of the principles enshrined in the Convention on Human Rights and Biomedicine (Oviedo Convention, ETS No. 164, 1997).

When drafting the guide the DH-BIO relied in particular on the results of a symposium on the decision-making process regarding medical treatment in end-of-life situations, held by the Steering Committee on Bioethics (CDBI)1 on 30 November and 1 December 2010.

The co-ordination of this event was entrusted to the Chair of the CDBI, Ms Isabelle Erny (France). For the preparation of the symposium, the CDBI was able to draw on two reports – one by Professor Lucie Hacpille (France) on "Medical decisions in end-of-life situations and the ethical implications of the available options" and the other by Professor Roberto Andorno (Switzerland) entitled "Previously expressed wishes relating to health care – Common principles and differing rules in national legal systems".

A follow-up group was appointed to prepare a draft guide on support for the decision-making process based on the results of the symposium. The group, chaired by Ms Isabelle Erny, comprised Dr Béatrice Ioan (Romania), Professor Andreas Valentin (Austria) and the symposium general rapporteur, Professor Régis Aubry (France).

In December 2012, the DH-BIO agreed to publish for consultation the draft guide prepared by the follow-up group. The public consultation ran from February to April 2013 and allowed comments to be collected from representatives of the various sectors concerned (particularly patients, health professionals, bioethics experts and human rights lawyers).

The version of the draft guide revised to take account of the comments received was approved by the DH-BIO at its 4th plenary meeting (26-28 November 2013). It was sent to the Steering Committee for Human Rights (CDDH) which took note of it and then sent it to the Committee of Ministers of the Council of Europe for information.

[4] In 2012, following a reorganisation of intergovernmental structures, the Steering Committee on Bioethics (CDBI) became the Committee on Bioethics (DH-BIO). The DH-BIO is a subordinate committee of the Steering Committee for Human Rights (CDDH).

Chapter 1
Introduction

Progress in the health field and advances in medicine – particularly developments in medical technology – enable life to be prolonged and increase prospects of survival. By turning what used to be regarded as acute or rapid progression illnesses into chronic or slow progression illnesses, they give rise to complex situations and are unquestionably rekindling the debate on the end of life and the framework in which decisions are taken on medical treatment in end-of-life situations.

The end of life and the questions it raises in terms of dignity of the person is one of the current concerns of Council of Europe member states,[5] despite variations in cultural and societal approaches. The principles established by the Convention for the Protection of Human Rights and Fundamental Freedoms,[6] and more specifically by the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine,[7] form an ethical and legal frame of reference through which member states endeavour to find common, co-ordinated responses to the questions which arise in society, with the aim of ensuring that human dignity is protected.

These provisions, based on shared values, can be applied to end-of-life situations dealt with through medical care and health systems, and some even provide direct responses to such situations (see for example, Article 9 of the Convention on Human Rights and Biomedicine, relating to previously expressed wishes).

Purpose

This guide presents, in an informative, summarised form, the principles that can be applied to the decision-making process regarding medical treatment in specific end-of-life situations. The intention is for these principles to be applied regardless of the distinct legal framework in each state. The guide is aimed primarily at the healthcare professionals concerned, but it is also a potential source of information and a basis for discussion for patients, their family and close friends, all those providing support, and associations dealing with end-of-life situations. Some elements in this guide could also serve as material for many current debates on end-of-life issues.

The aims of this guide are as follows:

► **to propose reference points** for the implementation of the decision-making process regarding medical treatment in end-of-life situations. Among other things, these should make it possible to identify the parties involved in the process, the different stages of the process, and the factual elements that influence decisions;

[5] The Council of Europe is an intergovernmental organisation currently comprising 47 member states including the 28 European Union states; its role is to safeguard and foster the ideals and principles which are its member states' common heritage: democracy, human rights and the rule of law.
[6] European Convention on Human Rights, ETS No. 5.
[7] Convention on Human Rights and Biomedicine (ETS No. 164), adopted in 1996 and opened for signature in Oviedo (Spain) in 1997 (Oviedo Convention).

► to bring together both normative and ethical reference works and elements relating to good medical practice, which will be useful for health professionals dealing with the implementation of the decision-making process regarding medical treatment in end-of-life situations. The guide may also provide reference points for patients and their close friends, families or representatives to help them understand the issues involved and hence take an appropriate part in the process;

► to contribute, through the clarification it provides, to the overall discussion on the decision-making process in end-of-life situations, particularly the complex circumstances encountered in this context, as it creates an opportunity to outline a number of issues and debates to which different European countries sometimes provide a diverse range of responses (see the boxes throughout the text).

The aim of this guide is not to take a position on the relevance or legitimacy of one decision or another in a given clinical situation. There is no doubt, however, that the impact of the expected decision adds to the complexity of the situation.

It relates to the specific context of the end of life, a situation in which the main purpose of any medical treatment is palliative, focusing on the quality of life or, at the very least, the control of symptoms that are liable to impair the quality of the end of a patient's life.

Furthermore, while the main thread of any discussion on decisions regarding medical treatment must be respect for the individual's dignity and autonomy, clinical experience shows that at the end of life patients may be vulnerable and find it difficult to express opinions. In addition, there are situations in which decisions are sometimes taken when patients are no longer able to express their wishes. Lastly, in certain cases, patients may express, entirely of their own accord, the legitimate wish not to take decisions on their medical treatment.

At all events, in uncertain and complex situations like those generated by the end of life, decisions should be the culmination of a proactive, collective process ensuring that patients are placed at the centre of decisions, carrying out as far as possible what would have been their wishes had they been able to express them, avoiding the biases of inevitable subjectivity and allowing as far as possible for treatment to be adjusted in line with the patient's changing state.

Scope

The elements below focus very specifically on the following points:

► the **decision-making process** and not the content of decisions (where certain types of decision are presented, it is simply to illustrate arguments relating to the process);

► the decision-making process as it applies to end-of-life situations;

► the decision-making process regarding medical treatment, including its implementation, modification, adaptation, limitation or withdrawal.

For the purposes of this guide, end-of-life situations are understood as those in which a severe deterioration in health, due to the evolution of a disease or another cause, threatens the life of a person irreversibly in the near future.

NB. It should be noted that this guide, which focuses on the decision-making process, does not address the issues of euthanasia or assisted suicide, which some national legislations authorise and regulate through specific rules.

The aspects described below apply whatever the place and the conditions in which the end-of-life situation is being dealt with, whether in hospital, in a medico-social establishment such as a retirement home, or at home, and irrespective of the department or ward in which the person is being treated (emergency, intensive care, cancer, etc.). Adjustments are of course required to take account of the constraints which are specific to each individual situation. For example, the question of time scales is important and the process cannot be organised in the same way in an emergency as it would in the context of an anticipated end-of-life situation.

However, due regard must always be shown for the principle that patients' opinions should be sought in the light of the treatment options being considered, and that collective discussion processes become essential when patients are unwilling or unable to take part directly in the decision-making process. The authors of this guide also recognise that specific features can make some end-of-life situations particularly complex. It would be worth looking at some of these situations individually so that necessary adjustments to the process can be singled out (for example, end-of-life situations in the neonatal field).

Chapter 2

The ethical and legal frames of reference for the decision-making process

The decision-making process regarding medical treatment in end-of-life situations raises questions concerning the main, internationally acknowledged ethical principles, namely autonomy, beneficence, non-maleficence and justice. These principles form part of the fundamental rights enshrined in the European Convention on Human Rights and are transposed into the field of medicine and biology by the Convention on Human Rights and Biomedicine. These principles are interrelated and this should be taken into account when considering their application.

A. The principle of autonomy

Respect for autonomy begins with recognition of the legitimate right and the capacity of a person to make personal choices. The principle of autonomy is implemented in particular through the exercise of free (without any undue constraints or pressure) and informed (following the provision of information appropriate to the proposed action) consent. The person may change his or her mind at any time with regard to consent.

Prior information is an essential contributing factor to the exercise of the principle of autonomy. For people to take informed decisions, they must have access to information that is appropriate in terms of content and form. This information should be as complete as possible. Patients must be informed of the purposes and the anticipated risks and benefits of treatment. Moreover, the manner and form in which information is supplied are particularly important and must be suited to the person concerned. In this context it is important to be satisfied that the information provided has really been understood by the patient. The quality of the dialogue between health professionals and patients is thus an essential element for the patient's rights. This dialogue must also make it possible to anticipate possible future decisions in relation to situations that may be encountered, or even arrive suddenly.

The principle of free and informed consent, given prior to any intervention on the person concerned, is closely linked to the right to respect for private life enshrined in Article 8 of the European Convention on Human Rights. The same is true of the patient's consent to have his or her personal data accessed and communicated to third parties under conditions ensuring respect for confidentiality of the data.

This principle and the right to withdraw consent at any time are enshrined in Article 5 of the Convention on Human Rights and Biomedicine. Furthermore, Article 6 of this convention sets out the provisions designed to ensure that particularly vulnerable persons, who are not able to give their consent, are protected.

More specifically and connected directly with end-of-life situations, Article 9 of the Convention on Human Rights and Biomedicine provides for the possibility of people expressing in advance their wishes concerning the end of their lives, in the event that they are no longer able to do so

when the decision has to be taken, and the duty of doctors to take account of these wishes when assessing the situation.

An end-of-life situation is very often a moment of high vulnerability in a person's life, which can have a profound impact on the patient's ability to exercise autonomy. Assessing the extent of patients' autonomy and hence their actual ability to be involved in decision making is therefore one of the main issues in the end-of-life decision-making process. Inquiring into patients' desires or previously expressed wishes is therefore an indispensable part of the decision-making process, particularly among patients whose functional capacities have declined to such an extent that their ability to take part in the process is restricted.

Autonomy does not imply the right for the patient to receive every treatment he or she may request, in particular when the treatment concerned is considered inappropriate (see section B.2 below). Indeed, health-care decisions are the result of a reconciliation between the will of the patient and the assessment of the situation by a professional who is subject to his or her professional obligations and, in particular, those arising from the principles of beneficence and non-maleficence as well as justice.

B. The principles of beneficence and non-maleficence

The principles of beneficence and non-maleficence refer to the doctor's dual obligation to seek to maximise the potential benefit and to limit as much as possible any harm that might arise from a medical intervention. The balance between benefits and risks of harm is a key aspect of medical ethics. The potential harm may not be only physical but could also be psychological, or take the form of infringement of the individual's privacy.

On a normative level, these principles are reflected in the right to life enshrined in Article 2 of the European Convention on Human Rights and the right to protection from inhuman and degrading treatment established in its Article 3. They also form the basis for the assertion of the primacy of the human being over the sole interest of society or science set out in Article 2 of the Convention on Human Rights and Biomedicine and, more precisely, the obligation to comply with professional obligations and standards laid down in Article 4 of this convention.

More specifically, in application of these principles, doctors must not dispense treatment which is needless or disproportionate in view of the risks and constraints it entails. In other words, they must provide patients with treatment that is proportion-ate and suited to their situation. They also have a duty to take care of their patients, ease their suffering and provide them with support.

1. The obligation to deliver only appropriate treatment

Without prejudice to respect for the patient's free and informed consent, the first prerequisite for the implementation or continuation of any treatment is a medical indication.

When assessing whether a form of treatment is appropriate in view of the particular situation of the patient concerned, the following issues need to be addressed:

► the benefits, risks and constraints of medical treatment according to the anticipated effects on the patient's health;

► their appraisal in view of the expectations of the person concerned. This results in an assessment of the "overall benefit", which takes account of the benefit in terms not only of the results of the treatment of the illness or the symptoms but also of the patient's quality of life and psychological and spiritual well-being.

In some cases, this appraisal leads to the conclusion that the treatment, even in response to a medical condition, is disproportionate when the risks and/or the scale of the constraints and the means required to implement it are compared with the anticipated benefits.

When, in a given situation, the treatment that is being contemplated or implemented will not yield or no longer yields any benefits, or is regarded as being clearly disproportionate, beginning or continuing to implement it can be described as "therapeutic obstinacy" (or unreasonable obstinacy). In such cases, the doctor may legitimately decide, in his or her dialogue with the patient, not to implement the treatment or to withdraw it.

There is no obvious means of measuring whether treatment is disproportionate that would apply to all individual situations. Even though there are medical criteria from evidence-based medicine, which can be used to evaluate risks and benefits, whether or not treatment is proportionate will be assessed in the light of the patient's situation as a whole. The relationship of trust between doctors, carers and patients is instrumental in the assessment of the proportionality of treatment. Disproportionality of treatment will be defined in particular according to the development of the illness and the patient's reaction to the treatment; this is what will determine whether the medical indication needs to be called into question. In many cases, the possible disproportionality emerges in the course of the discussion between doctors, carers and patients about the purpose and the expected benefits and potential risks of treatment.

In end-of-life situations, the assessment of "overall benefit" plays a particularly important role in determining the suitability of a treatment whose purpose may change (shifting from a curative to a palliative purpose for example). In these situations, the prolonging of life must not in itself be the sole aim of medical practice, which should attempt just as much to relieve suffering. The difficulty of any medical decision at the end of life is to ensure that the patient's autonomy and dignity are respected and that a balance is struck between the protection of life and the person's right to be relieved of suffering if possible.

2. The concept of needless or disproportionate treatment likely to be limited or withdrawn

In addition to its technical aspect, the care, in its broad sense, administered to patients includes the attention paid by health professionals to any person made vulnerable by illness or by an infringement of physical integrity. The concept of care therefore comprises treatment involving a medical procedure, but also other types of care designed to satisfy patients' everyday needs and not requiring any particular medical skill (for instance, personal hygiene and comfort).

Treatment, strictly speaking, covers interventions whose aim is to improve a patient's state of health by acting on the causes of the illness. The goal of such treatment is to cure patients of an illness or to act on its causes in order to reduce its impact on the patient's health. Treatment also covers interventions which have no bearing on the aetiology of the main illness from which the patient is suffering but on the symptoms (for example, analgesic treatment to alleviate pain) or which are responses to an organ dysfunction (such as dialysis, mechanical ventilation).

It may be decided to withdraw or limit a treatment as specified above, which does not provide any benefit or has become disproportionate. Limitation of treatment can mean both progressively withdrawing it and reducing the doses administered so as to limit side effects and increase beneficial effects.

In end-of-life situations, the purpose of treatment and care is, above all, to improve the patient's quality of life. This objective may sometimes require certain types of treatment to be implemented or increased; this is especially the case for treating pain or any symptom causing discomfort.

It is also important to bear in mind that while the question of limiting or withdrawing a treatment which no longer provides any benefit or has become disproportionate may be raised in end-of-life situations, there should be no question of discontinuing care, including palliative treatment, designed to preserve the patient's quality of life, as this is always necessary, embodying respect for the human person in medical practice.

■■■ Disputed issues

The question of limiting, withdrawing or withholding artificial hydration and nutrition

Food and drink given to patients who are still able to eat and drink themselves are external contributions meeting physical needs, which should always be satisfied. They are essential elements of care which should be provided unless the patient refuses them.

Artificial nutrition and hydration are given to a patient following a medical indication and imply choices concerning medical procedures and devices (perfusion, feeding tubes).

Artificial nutrition and hydration are regarded in a number of countries as forms of treatment, which may therefore be limited or withdrawn in the circumstances and in accordance with the guarantees stipulated for limitation of withdrawal of treatment (refusal of treatment expressed by the patient, refusal of unreasonable obstinacy or disproportionate treatment assessed by the care team and accepted in the framework of a collective procedure). The considerations to be taken into account in this regard are the wishes of the patient and the appropriate nature of the treatment in the situation in question.

In other countries, however, it is considered that artificial nutrition and hydration do not constitute treatment which can be limited or withdrawn, but a form of care meeting the individual's basic needs, which cannot be withdrawn unless the patient, in the terminal phase of an end-of-life situation, has expressed a wish to that effect.

The question of the appropriate nature, in medical terms, of artificial nutrition and hydration in the terminal phase is itself a matter of debate. Some take the view that implementing or continuing artificial hydration and nutrition are necessary for the comfort of a patient in an end-of-life situation. For others, the benefit of artificial hydration and nutrition for the patient in the terminal phase, taking into account research in palliative care, is questionable.

C. The principle of justice – Equitable access to health care

The right of equitable access to health care of appropriate quality is enshrined in Article 3 of the Convention on Human Rights and Biomedicine. Equity means first and foremost the absence of discrimination, with the requirement for each individual to be able to obtain, in practice, the care available. This principle implies that available resources should be distributed as fairly as possible. It is now generally accepted that palliative care is an integral part of health care, as asserted in Recommendation Rec(2003)24 of the Committee of Ministers of the Council of Europe on the organisation of palliative care. In this context, it is therefore for governments to guarantee equitable access to such care for anyone whose state of health requires it.

The explanatory memorandum of the recommendation also points out that "doc-tors are not obliged to continue treatments that are patently futile and excessively burdensome to the patient", and that the patient may refuse such treatment. The aim of palliative care is therefore to provide the best possible quality of life for patients. The latter must be offered both active care designed to control pain and other symptoms and provided with the necessary support in coping with their psychological or social problems and, where appropriate, spiritual support. It would also be helpful to provide support for family members who are often under considerable stress.

To meet the challenges posed by end-of-life situations, one of the priorities is most certainly to broaden access to palliative care regardless of how it is organised (specialist services or dedicated beds in establishments, at home, etc.). Steps should be taken at least to foster a palliative approach among health-care professionals and within health-care services so that everyone's suffering can be dealt with satisfactorily without discrimination and that, over and above access to palliative care, respect is shown for human rights, especially each individual's right to choose the place and the conditions of his or her end of life.

Chapter 3
The decision-making process

Before describing the different phases of the decision-making process, it is important to specify the different parties involved and their respective roles in the process. Clarifying each individual's role makes it possible, bearing in mind the complexity of certain situations and the related decisions, to avoid stumbling blocks and risks of conflict. The aim of the process must be to reach a consensus once each party involved has put forward his or her point of view and arguments.

A. The parties involved in the decision-making process and their roles

An analysis of the decision-making process shows that, in addition to the patient and his or her doctor, there are other parties that are involved to highly varying degrees. First, there are those close to the patient: people who, in different capacities, will stand in for and represent the patient when he or she wishes or is no longer able to take part in the decision-making process, as well as offering the patient support, such as family, close friends and various other people providing assistance. Then there are all the members of the care team.

The following description of the parties involved in the decision-making process reflects those parties' diverse range of roles (decision maker, legal support, witness, support provider, etc.); it also takes account of the diverse range of national legal situations. It should be noted that on occasion different roles can be performed by the same person (for example, parents can simultaneously be their child's legal representative, etc.).

1. The patient, his or her representative, family members and other support providers

The principal party in the decision-making process with regard to medical treatment in end-of-life situations is the patient himself or herself. Patients may benefit from the presence of their family, close friends or other people in their entourage in so far as they can provide support. When the patient is incapable or no longer capable of making decisions, substitution arrangements make it possible to ensure that the decisions taken are as close as possible to what he or she would have decided and wished if he or she had been able to take part in the decision-making process, or to ensure that the decision taken will be in the patient's best interests. These arrangements are generally provided for in domestic legislation. When the patient cannot be directly involved in the decision-making process, having a collective discussion meets the requirement for objectivity, which is essential for the patient's protection.

a. Patients

Patients capable of taking part in decision making

If patients are able to take part in the decision-making process, they can draw up a care plan with the doctor and the medical team on the basis of the information and guidance provided by the doctor in the context of the relationship of trust which they have developed. On no account can there be any intervention on the patient without his or her consent, except in emergency situations and provided that the patient has not previously refused the intervention.

Accordingly, doctors must accept refusals of treatment clearly expressed by the patient, but may suggest, where possible, that the latter takes time to think and/or consult other people. In all cases, it is appropriate to allow the patient time to think things over before making a decision.

Furthermore, patients who are capable of deciding for themselves may wish nonetheless for other persons to be consulted or to be guided or represented either by a "natural" provider of support (a family member) or by a "designated" person such as a person of trust. They may also, on their own initiative, ask to be assisted in their decision by a collective procedure.

In some especially complex situations, when, for example, a patient requests continuation of treatment which is no longer appropriate or, on the contrary, withdrawal of treatment – such withdrawal having the potential to adversely affect his or her quality of life – it may also be suggested that he or she should seek other people's advice and, in particular, consult other health professionals before a decision is reached.

Patients whose ability to play a full and valid part in the decision-making process is in some doubt

In an end-of-life situation, questions are frequently raised about the patient's ability to play a full and valid part in the decision-making process (for instance, because of developments in certain illnesses affecting the patient's cognitive faculties). In such situations, if there is any doubt about the patient's ability, it must be assessed. The assessment should be assigned, as far as possible, to an impartial assessor, not directly involved in the decision-making process or in the patient's medical care. The assessment of the patient's ability to exercise his or her autonomy should be documented.

■■■ **Focus on:**

Assessing the patient's ability to take medical decisions for himself or herself

To assess a person's degree of ability to take a medical decision for him or herself, it may be useful to take into account the following elements:

– *ability to understand*: patients should be able to understand essential information about the diagnosis and the related treatment and be capable of showing that they understand;

– *ability to appraise*: patients should be able to appraise the situation in which they find themselves, recognise the problem and evaluate the consequences of treatment in their own situation in relation to their own scale of values or view of things;

– *ability to reason*: patients should be able to reason, compare options proposed and weigh up their risks and benefits. This skill depends on the ability to assimilate, analyse and handle information rationally;

– *ability to state a choice*: patients should be able to make a choice, and express and substantiate it.

Apart from situations when a person is totally incapable of expressing a wish (as for example in a vegetative state), even where he or she does not seem capable of expressing free and informed wishes, it is necessary to view that person as a human being in the fullest sense, capable of partly perceiving or understanding what is said and of participating as much as possible in the decision-making process. It is therefore recommended that he or she be systematically informed and have it spelt out as clearly as possible and in a manner suited to the level of comprehension, what the issues and the potential courses of action are, even though the patient will be covered by legal protection measures. Any opinions and wishes that patients may communicate and the reactions they may have at this point should be taken into account and, as far as possible, guide the decision to be taken concerning them.

Patients who cannot or can no longer participate in the decision-making process

Where patients cannot take part in the decision-making process (due to a coma, brain damage, an advanced-stage degenerative disease, etc.), the decision will be taken by a third party according to the procedures laid down in the relevant national legislation.

Even in situations in which patients cannot take part in the decision, they remain a party in the process. Although unable to express their wishes concerning the arrangements for the end of their lives at the time that the decision must be taken, patients can be involved in the decision-making process nonetheless by means of any previously expressed wishes. This expression of the patient's wishes in advance can take various forms. For example, the patient may have confided his or her intentions to a family member, a close friend or a person of trust, appointed as such, so that they can bear witness to and pass on the patient's wishes when the time comes. The patient may also have drawn up advance directives/a living will or granted powers of attorney to a third party, covering exactly the situation for which a decision must be taken.

■■■ **Focus on:**

The formal arrangements for previously expressed wishes

There are various legal arrangements:

– *Formal statements* (or "advance directives", which are sometimes referred to as "living wills" (see box below)) are written documents drawn up by a person having legal capacity (who has attained majority and is able to express a free and informed wish) containing provisions relating to medical treatment in the event that he or she is no longer capable of taking part in the decision-making process. The holder or bearer of the statement does not speak on behalf of the person who made the statement.

– *Powers of attorney* on health-care questions enable persons known as granters to appoint persons known as attorneys (who must agree to this role) to express on their behalf their wishes concerning the medical treatment to be given to them if they are no longer capable of taking part in the relevant decision. In French, these powers are sometimes referred to as a *mandat de protection future* (powers of future protection). Any suit-able person, who possesses legal capacity, may be appointed, including a family doctor, a family member, a close friend or a person of trust, etc. The attorneys may also clarify ambiguous provisions of formal statements or provide clarification concerning

other situations not mentioned in them or arising as the illness progresses. However, attorneys can act only in accordance with their powers and in the granter's interest.

In view of their importance in the decision-making process as a means of ensuring the protection of the patient's wishes, special attention should be paid, in the organisation of the health system, to the arrangements for previously expressed wishes regardless of their legal force. This is a means of exercising patients' rights. All health system users and health professionals should be informed of the existence of such possibilities, how they are arranged and what their legal scope is.

A formal, written document appears to be the safest and most reliable way of making known one's wishes expressed in advance. Accordingly, written advance directives are the means that most directly reflect patients' wishes. When they exist, they should take precedence over any other non-medical opinion expressed during the decision-making process (by a person of trust, a family member or a close friend, etc.), subject, of course, to the fulfilment of a certain number of requirements to ensure their validity (authentication of the author, legal capacity of the author, appropriate content, length of validity, arrangements for them to be redrafted so that they can be kept as closely in line as possible with current developments, possibility for them to be revoked, etc.), and their accessibility (arrangements for them to be kept in such a way that the doctor can access them in good time).

■■■ **Focus on:**

The arrangements for the application of advance directives

► When to draw them up

In principle, advance directives must be drawn up by a person who has attained majority, with the legal capacity and the ability to express his or her wishes concerning the organisation of the end of his or her life. They may for instance be drawn up in anticipation of a potential accident with unforeseeable consequences or in cases of chronic illnesses in which the illness can be apprehended at each stage, neurodegenerative diseases affecting cognitive faculties in a fluctuating manner over time or mental illnesses such as severe depression, which affect patients' will, etc. It can, however, be difficult for a person who is still in good health to envisage in advance illness, dependency and the end of life. This difficulty in anticipating the future may affect the precision of the wishes expressed. Regardless of the legal scope of advance directives in any given legal system, they will always have more weight in the decision-making process if they correspond to the situation encountered and thus have been drawn up in the light of a specific medical context. This is even more the case when the patient is in a position to grasp the consequences of his or her illness.

► Term of validity and periodic renewal

Answers may differ on this point, depending on the pathologies. Periodic renewal of directives and limits on their validity make it possible to keep up with the situation encountered. However, with illnesses in which the patient's cognitive faculties deteriorate progressively over a long period, it must be possible to refer to wishes expressed well in advance, before the patient's cognitive condition is affected to the point that valid

restatement of his or her wishes becomes impossible. When a term of validity is set, the rules should state what must be done when advance directives expire but it has been impossible for the patient to restate his or her wishes. Can they be totally ignored? When all is said and done, they continue to offer an indication of the person's wishes. At all events, it is widely accepted that it should be possible to revoke advance directives.

► The need for formalism

The need for something written which makes it possible to authenticate a document is an undisputed requirement. Furthermore, the more binding force the legal rules assign to advance directives, the stricter it appears they must be about the way in which directives are expressed: validation by the doctor (attesting the patient's mental state and the reliability of the instructions) and countersignature by two witnesses, etc. Another issue concerns the arrangements for keeping the document depending on the legal force of the advance directives: should it be kept by the patient or entrusted to the doctor in attendance, the hospital authorities, a legal professional, such as a solicitor, or the patient's person of trust, and should it be recorded in a national register?

In any case, from a formal viewpoint, either advance directives are seen as a clinical tool, stemming from the doctor–patient relationship and contributing to a decision-making process which shows respect for patients, or they are viewed as an administrative document which, provided the validity criteria are met, is binding on the doctor. Between these two schematic viewpoints, there is a whole range of intermediate situations. At all events, advance directives might be regarded as an instrument conducive to dialogue between the patient and the doctor or the medical team; this would make them a substantial contributing factor to the framing of the decision in the context of the collective discussion process.

The legal status and binding force of advance directives vary, and are still highly disputed issues. However, the importance of arrangements such as advance directives should be brought to the attention of health-care professionals, and doctors in particular. When drawn up with the assistance of a doctor, they make it possible to anticipate the decisions to be made, bearing in mind the evolution of the illness and the various options which will arise. Their value, both for patients and for doc-tors, is obvious in certain chronic and degenerative illnesses. This aspect should be included in the training given to doctors and health-care professionals.

■■■ Disputed issues

► Limits and contents of advance directives

Can advance directives relate to a request to limit or cease treatment in certain predetermined situations, or should they relate only to choices of types of treatment to be implemented? Besides treatment, should they address other questions relating to the organisation of care and the patient's living conditions? More generally, must they be specific and precise, or general in scope? Both propositions have pitfalls: if they are too precise, they leave no room for any medical interpretation with a view to adaptation, whereas if they are too general, they make it impossible to be certain that the wish expressed will have anything to do with the clinical situation. Advance directives may, however, only relate to possibilities authorised by the law.

► The legal status of advance directives varies considerably according to each country's relevant statutory provisions.

The Convention on Human Rights and Biomedicine requires doctors to "take into account" previously expressed wishes (Article 9). States then have the choice whether or not to give previously expressed wishes binding force. The Committee of Ministers of the Council of Europe attaches major importance to such wishes and in Recommendation(2009)11 on principles concerning continuing powers of attorney and advance directives for incapacity, it recommends that member States "promote self-determination for capable adults in the event of their future incapacity, by means of continuing powers of attorney and advance directives". It also stipulates that "States should decide to what extent advance directives should have binding effect" and points out that "advance directives which do not have binding effect should be treated as statements of wishes to be given due respect".

In the debate on the extent to which advance directives should be binding, some argue that giving them binding force places all the responsibility for the decision on the patient whereas under arrangements in which they are not binding, doctors assume responsibility for the decision. Others argue that advance directives reflect the will of the person at the time that they are written and cannot anticipate how this may change as the illness develops – changes of mind of this sort are seen in people who are still capable of expressing their views.

It should be noted that even in countries which explicitly recognise the binding force of advance directives, there is broad acceptance that there may be certain reasons authorising doctors not to follow the patient's wishes. For example, when they have been formulated several years before the onset of the incapacity or where there have been significant medical advances since the date when the advance directives were drawn up which have a direct impact on their content.

b. The legal representative

When the patient is not able to give full and valid consent to a medical intervention because of his or her age (being a minor), mental disability, disease or for similar reasons, the law ensures his or her protection by appointing a representative. A distinction should be made between the legal representative, whose nature (physical person, institution, authority) and role are determined by national law, and other persons appointed by the patient to act on his or her behalf in the decision-making process, such as persons of trust. A distinction should also be drawn between the legal representative and the attorney, who acts on behalf of the patient at the latter's request, in strict compliance with the powers assigned to him or her (see paragraph c. Attorney below).

In some legal systems, legal representatives have a decision-making role. They may grant authorisation to carry out a medical intervention on a legally protected person, either in the general framework of their role or within the limits specified by a judge. In all cases, the legal representative can act only in the interests of the protected person.

Whatever the legal system, in accordance with the principle of respect for the person's dignity, the fact that there is a legal representative should not exempt the doctor from involving the

patient in the decision-making process, if the latter, despite lacking legal capacity, is able to participate him or herself.

It is widely accepted that the objection of persons who lack the legal capacity to give their free and informed consent to a medical intervention should always be taken into account.

In the case of minors, their opinion shall be viewed as an increasingly decisive factor, in proportion to their age and their capacity for discernment.

c. Attorney

The patient may have been able to express his or her end-of-life wishes to a third party under a power of attorney, the scope of which may cover more than decisions regarding medical treatment (relating also to property, place of residence or accommodation, etc.). Attorneys act for the patient in accordance with the powers assigned to them. They transmit the person's wishes to the care team and ensure that they are taken into account.

d. Person of trust

The definition and role of the person of trust (sometimes referred to as "personal advocate" or "surrogate") may vary according to national legislation. However, the notion of "person of trust" refers to persons chosen and expressly designated as such by the patient. They are generally to be differentiated from legal representatives and attorneys. Their role is to assist and support the patient throughout the latter's illness. When the patient is no longer able to express his or her wishes, the person of trust may bear witness to what those wishes would be. Persons of trust may also be entrusted with advance directives and disclose them to the doctor at the appropriate time.

e. Family members and close friends

Notwithstanding the duties of legal representative which the legal apparatus may assign to certain family members (for example, parents are the legal representatives of their minor children, or a person may be the legal representative of his or her partner), the role of the family may vary from country to country and according to the social and cultural context. The same applies to persons who are "close" to the patient and have friendly or emotional ties with him or her of such a nature that they may be closer still to the patient than his or her family. Sometimes, moreover, patients will choose a person from among this circle of close friends to act as their person of trust, either because their family ties have loosened or because they want to relieve their family members of a burden.

The role both of the family and of close friends may also vary depending on the place where the patient is cared for (for example, patients at home are closer to their entourage).

Be that as it may, even where they have no legally defined role in the decision-making process, consultation with family members and close friends, albeit subject in principle to the patient's consent, is especially important in view of their emotional ties and intimacy with the patient.

Experience has shown however that, within the same family, approaches to the end of life can be very different and that it may be difficult for the care team to deal with family conflicts. In

such situations, the existence of previously expressed wishes, formalised in writing, especially advance directives, or the appointment of a person of trust or power of attorney, can be helpful.

f. Other support providers

As to the various other support providers (such as members of associations, volunteers, etc.), in principle, over and above the support that they provide to the person, these parties, who are not members of the group providing care, even in the broad sense, do not intervene in the collective decision-making process. However, these different support providers may possess information (on existing advance directives, on the patient's wishes, about his or her living environment, etc.). As such, they may be considered as witnesses to the patient's wishes or as a source of information, and it is certainly useful and sometimes essential to consult them. While they are not involved in the decision-making process, their presence often makes it possible to offer patients human or spiritual support, which should not be neglected at this moment in their lives.

2. Carers

a. The doctor

Because of their ability to appraise the patient's situation from a medical viewpoint and because of their professional responsibilities, doctors have a major, if not primary role in the decision-making process. They provide patients or other persons involved in the decision-making process with the necessary medical information.

They prepare, with the patients, care and treatment plans. Where the patient is capable of expressing free and informed wishes, they can help him or her to take decisions. Where patients are not or no longer able to express their wishes, doctors are the people who, ultimately, at the end of the collective decision-making process, having involved all the health-care professionals concerned, will take the clinical decision guided by the best interests of the patient. To this end, they will have taken note of all the relevant elements (consultation of family members, close friends, the person of trust, etc.) and taken into account any previously expressed wishes. However, it should be noted that in some countries this role of final decision maker, in cases where the patient cannot be involved in the process, does not fall to doctors, but is assigned to a third party (for example, the legal representative). Nonetheless, in all cases, doctors are the ones to ensure that the decision-making process is properly conducted and, in particular, that any wishes expressed previously by the patient are taken into account and any treatment that is needless or disproportionate is avoided.

b. The care team

This is the team taking care of the patient and includes nurses, care assistants and, where appropriate, psychologists, members of the paramedical professions, such as physiotherapists, etc. The role of each member of the care team in the decision-making process may vary according to the country. In any case, the role of each member must be determined in the framework of the decision-making process. These professionals, who take care of the patient on a daily basis and are often close to him or her, contribute to the decision-making process not only by providing medical information but also crucial details concerning patients, such as information on their living environment, their background and their beliefs.

The care team can also be taken to mean something broader, including all the people involved in the overall care of the patient. For instance, because of their knowledge of people's material, family and emotional environment, social workers may have access to information that can be used to assess patients' situations (such as means of judging whether it is possible for them to return home), which are not necessarily available to health professionals.

c. Other bodies potentially involved in the decision-making process

In a situation of uncertainty, a clinical ethics committee may become involved in order to assist, by means of ethical opinions, in the discussions that take place as part of the decision-making process. Depending on the arrangements made, such committees may be involved in the process either systematically or on request (from the medical team, the patient or the patient's entourage).

Bearing in mind the complexity of end-of-life situations, there may be a risk of conflicts between the different parties over acceptable solutions (among members of the care team, within the family, etc.). It may prove necessary to turn to a third party such as a specialist body fulfilling a mediation role. Furthermore, some legal systems provide for the intervention of a court.

B. The deliberative process and decision making

For the purposes of the discussion, this chapter takes the highly schematic approach of identifying a number of phases, taking into account the nature and aims of the activities being carried out, the parties involved and the setting in which the end-of-life situation occurs (home, hospital or elsewhere).

This succession of phases does not necessarily represent a chronological sequence, which it is absolutely essential to follow. The main point is to make it possible to identify the key components of the decision-making process while also taking account of the time constraints that can exist in some specific clinical situations.

NB. The subject of this chapter is the decision-making process itself. As pointed out at the beginning of the guide, its aim is not to discuss the content, the relevance or the legitimacy of the decision which will ultimately be taken in a given clinical situation.

1. Preliminary remarks

Before looking at the various phases of the decision-making process in detail, we should reiterate the following points:

► **The patient should always be at the centre of any decision-making process**. This holds true whatever the patient's legal capacity or his or her de facto ability to take the decision or participate in it. In principle, patients are the parties who must decide on and make choices concerning the end of their lives. Their direct involvement may vary, however, depending on their personal situation, which can be affected to varying degrees by their state of health, in which case the decision-making process can be adjusted accordingly.

► **The decision-making process takes on a collective dimension when the patient is not willing or able to participate in it directly**. Where patients do not wish, cannot or are no longer able to take part in the decision-making process or express the need to be assisted in the process themselves, a collective decision-making process should:

- provide safeguards when the decision is taken by a third party;
- furthermore be suited to the situations and complex choices arising from an end-of-life situation.

► **In principle, the collective decision-making process in end-of-life situations is made up of three main stages**:

- an **individual** stage: each party in the decision-making process forms his or her arguments on the basis of information gathered on the patient and the illness;
- a **collective** stage: the various parties – family, close friends and health-care professionals – take part in exchanges and discussions, providing different perspectives and complementary viewpoints;
- a **concluding** stage: when the actual decision is taken.

► **Patients and, where appropriate, any other people concerned** (legal representatives, attorneys and persons of trust or even their family members and close friends), must always have access to the information corresponding to their role in the decision-making process. Unless they specify otherwise, patients must always be given the requisite information on their state of health (diagnosis, prognosis), the therapeutic indications and possible types of care.

2. Different phases of the decision-making processes in end-of-life situations: description and analysis

a. The starting point of the process

The starting point of the process is the same as for any other situation requiring a decision on therapeutic or care options. First a medical indication is to be defined and then the balance is to be assessed between the risks and benefits of the treatments considered, irrespective of the curative or palliative nature of the care plan. The decision-making process is thus initiated by:

- ► the care team, which regularly assesses whether any treatment already set up or planned meets the requirement of being beneficial to the patient (for example, relieving or reducing suffering) and not harming him or her;
- ► any of the members of the care team expressing doubts about the therapeutic approach adopted or planned in view of the patient's specific situation;
- ► any comment or complaint made by the patient, his or her representative or person of trust, a member of his or her entourage (family, close friends, support providers), raising questions about the established care plan.

b. Definition of the problem

If any concerns have been expressed by one of the parties involved about the care and/or the support being provided, it is often important to clarify the underlying questions, to determine precisely where the problem lies and to elucidate its causes, taking into account the particular situation of the patient.

Questions can relate to any of the following matters:

- the appropriateness of implementing or continuing or, conversely, limiting or withdrawing treatment which is likely to have an impact on the quality of the patient's life in its very last phase, or on the process of dying;

- the meaning of a complaint or request (for example, pain-related complaints or requests for pain relief). It is important to interpret any fears and expectations expressed and decipher those elements, which might influence future treatment choices or reflect poor management of symptoms of distress (such as pain);

- differing opinions among the parties concerned about the patient's quality of life, the need to control certain symptoms or other matters.

c. Developing a line of argument

This phase is important in the framework of a collective process where the patient cannot take part in the decision-making process or has requested help with it. In principle, the doctor and the care team, in a broad sense, intervene in the decision-making process and, where appropriate, and the patient cannot, the patient's legal representative. Previously expressed wishes (such as advance directives and powers of attorney) are of course sought out and taken into account. Family members, close friends and other support providers are consulted, unless a prior objection has been expressed by the patient.

Establishing an individual line of argument

Each party in the collective procedure must be aware of his or her role and in which capacity he or she intervenes in the process. Every professional involved in this process takes responsibility for his or her actions, whatever his or her position in the team.

Each party must analyse his or her motivations (for example in the light of his or her professional practice), bear in mind that some of his or her reasoning may be subjective (deriving from personal experience, ideas and outlooks) as well as being influenced by his or her personal points of reference (ethical, philosophical, religious, etc.) and try to be as objective as possible.

Each party must base his or her arguments on factual elements when analysing the issues. The factual elements of the argument are to be identified at not less than three levels concerning:

- the disease and medical condition: diagnosis, prognosis, emergency, treatment plan, possibility of improvement, etc.;

- the patient's situation: assessment of his or her ability to participate in the decision-making process, legal status, sources of information about his or her wishes, quality of life and personal points of reference, the people/environment around him or her, his or her living conditions;

- health-care provision, what kind of care the health-care system can provide.

Collective discussion

While there can be no standard model since arrangements vary, in particular according to the care setting (hospital or home), the following steps are recommended prior to the exchanges and discussion:

- define the practical arrangements for the discussion (venue, number of participants, number of meetings planned, etc.);

- set a time frame while catering for an emergency response where necessary;

- identify who will take part in the discussion, specifying their role and obligations (decision maker, rapporteur, minute taker, co-ordinator/moderator, etc.);

- draw the attention of all participants to the fact that they must be prepared to change their minds when they have heard the views of the other people taking part in the discussion. In addition, everyone must be aware that the final view or opinion will not necessarily be in accordance with his or her own.

During the collective discussion, the way in which account is taken of the various opinions expressed should not be affected by any hierarchical relationships that may exist between the discussion partners or by any predetermined scale of values.

It is the nature of the arguments expressed which must give rise to a hierarchical ranking process facilitating decision making.

These requirements may prove too exacting in the context of care provision in the home – the collective procedure could in practice be just a joint meeting between the general practitioner, the nurse and the family carer.

Sometimes, where positions diverge significantly or the question is highly complex or specific, there may be a need to make provision to consult third parties either to contribute to the debate, to overcome a problem or to resolve a conflict. The consultation of a clinical ethics committee which could provide complementary insight may, for example, be appropriate. At the end of the collective discussion, agreement must be reached. This agreement is often found where the different opinions expressed intersect. A conclusion must be drawn and validated collectively, and then formalised in writing.

NB. The effect of the decision will need to be taken into account and anticipated as much as possible by considering in particular what additional measures will be needed in the event that the decision taken has an unexpected result.

d. Taking a decision

In all cases, prior identification of the person who will take the decision is necessary.

If the person deciding is the patient but, despite being able to take an autonomous decision, has nevertheless expressed the wish for a collective discussion:

- the conclusions of the discussion must be communicated to him or her with tact and restraint;
- patients must be allowed enough time to reach a decision.

NB. These factors are also relevant if the decision is taken by the legal representative or the patient's attorney.

If the decision is taken by the doctor in charge of the patient, it is taken on the basis of the conclusions of the collective discussion and will be announced:

- where appropriate, to the patient;
- to the person of trust and/or the entourage of the patient if he or she has so requested or is not able to express his or her will;
- to the medical team that took part in the discussion and cares for the patient;
- to third parties concerned who have taken part in the process in any capacity.

Once reached, the decision should be, as far as possible:

- formalised (a written summary of the justifications agreed), and include, where appropriate, the reasons why the advance directives have not been followed;
- kept in an identified place (such as the patient's medical records), meeting the conditions both for the medical data to remain confidential and for the medical team to have the necessary access to be able to review its conduct of the discussion and decision-making processes;

At all events, all decisions are covered by medical confidentiality.

■■■ Disputed issues

Decision on sedation for distress in the terminal phase

Sedation seeks, by means of appropriate medication, to reduce awareness to a degree which may extend to loss of consciousness. Its aim is to alleviate or remove the patient's perception of an unbearable situation (e.g. unbearable pain or unappeasable suffering) when every available treatment adapted to this situation has been offered and/or dispensed but has failed to bring the expected relief. The aim of sedation is not, therefore, to shorten life.

Nonetheless, the debate focuses on two points:

► Use of sedation not to relieve physical symptoms (such as dyspnoea), but to alleviate psychological or existential suffering.

If a patient's symptoms seem to be under control, but he or she continues to maintain that the suffering is unbearable and that he or she would like to be given sedation, how should the team deal with this request? Continuous deep sedation can lead to a loss of consciousness which could be irreversible and prevent the person from communicating with his or her family and friends. This could raise ethical discussions within the care team and with family members.

► Use of sedation with the secondary risk of shortening the time left to live.

Even though this is not its purpose, sedation can have a side effect in certain cases of accelerating the process of dying. There is much debate about the use of continuous deep sedation in the terminal phase up to the person's death, if in addition it is in conjunction with the cessation of all treatment.

For some, this result in itself poses a problem, particularly if the person cannot participate in the decision-making process (for example, brain damaged patients). For others, the decision is acceptable provided that the main intention is not to hasten the onset of the end of life but to relieve suffering.

e. Evaluation of the decision-making process after its application

Ex-post evaluation is one of the general principles of good practice. Evaluation of the decision-making process and the way it took place is particularly important in that it allows the medical team, based on its experience, to progress and better respond to similar situations.

For this purpose, keeping a concise yet accurate written record of the way in which the decision-making process was conducted in the case in question may be very useful to the team concerned. The aim is not, of course, to establish an instrument to monitor decision making retrospectively. This ex-post review of the implementation of the decision-making process should enable all parties involved and the team as a whole to understand on what basis the medical decision was taken and what the contentious issues were, and to enhance its own understanding of such situations in the future.

Chapter 4
Conclusions

Paying particular attention to the decision-making process regarding medical treatment at the end of life is a form of quality procedure, the main aim of which is to guarantee respect for patients who may be particularly vulnerable in an end-of-life situation.

In this context, it is essential to promote any measure that makes it possible to adhere as closely as possible to the patient's wishes, which can be expressed either by the patient him or herself or by means of advance directives.

The collective discussion process relates to the complex clinical situations in which patients find themselves at the end of life. In such situations, in which many ethical issues are raised, there is a need to discuss and compare arguments to enhance the response and formulate a decision that is geared to the situation and shows due respect for the patient.

Committee of Ministers Recommendation Rec(2003)24 on the organisation of palliative care, cited above, alerts states to the need to provide information and training, and conduct research in various issues relating to the end of life.

The decision-making process should in itself be the subject of:

► **information** for users of the health system, including their representatives from associations and their families. This information should relate to the tools enabling or facilitating dialogue between patients and doctors such as advance directives, the appointment of a person of trust and everyone's role and responsibility in the decision-making process in end-of-life situations;

► **training** for health professionals. In addition to specific end-of-life-related questions, training in the construction of individual thought processes and collective discussion is necessary so that each health professional can deal with the increasing frequency of complex situations involving many ethical issues in clinical practice. In both initial and in-service training contexts, the focus should be on the importance of learning such collective processes. The training could also be extended to the other professionals delivering care to persons in end-of-life situations (for example psychologists, social workers, chaplains).

► **specific studies**, taking into account the complexity and singularity of the situations encountered which are often the result of advances in medicine and medical techniques. These studies on decision-making processes should foster interdisciplinary approaches combining human sciences and medicine.

This brochure brings together key Council of Europe guidelines on one of the most important subjects faced by human beings – that is to say, coping with the issue of passing away. As with any challenging situation, help is needed both from individuals and from society in general – and this is all the more the case for those who are terminally ill.

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