Zusammenstellung aller Texte zur Debatte
von
Christian Frodl,
InteressenGemeinschaften Kritische Bioethik Deutschland


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Protection of the human rights and dignity of the terminally ill and the dying

Doc. 8421
21 May 1999

Report

Social, Health and Family Affairs Committee

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

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

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

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, defer the moment of death. As a result the quality of life of the dying is often ignored, as is their loneliness, their suffering and that of their families and of the care-givers.

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 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".

Since then, the European 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.

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.

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.

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

- the insufficient access to palliative care and good pain management;
- the often lacking treatment of physical suffering and psychological, social and spiritual needs;
- the artificial prolongation of the dying process by either using disproportionate medical measures or by continuing treatment without a patient's consent;
- the lack of continuing education and psychological support for health care professionals, working in palliative medicine,
- insufficient care and support for relatives and friends of terminally ill or dying patients, which otherwise could elevate human suffering in its various dimensions,
- the fear of patients to loose control of themselves and to become a burden to and totally dependent upon relatives or institutions;
- the lack or inadequacy of a social as well as institutional environment in which someone may take leave of his relatives and friends peacefully;
- the social discrimination of the phenomena of weakness, dying and death.

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:

- dying exposed to unbearable symptoms (e.g. pain, suffocating, etc);
- prolongation of the dying process of a terminally ill or dying person against his or her will;
- dying in social isolation and disintegration;
• dying under the fear of being a social burden;
• limiting of life-sustaining treatment due to economic reasons;
• insufficient provision of funds and resources for adequate supportive care of the terminally ill or dying.

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

• to ensure that palliative care be recognised as a legal entitlement of the individual in all member states;
• to provide equitable access to appropriate palliative care for all terminally ill or dying persons;
• to ensure that relatives and friends be encouraged to accompany the terminally ill or dying and be professionally supported in their endeavours. If family and/or private networks prove to be either insufficient or overstretched, alternative or supplementing forms of professional medical care are to be provided;
• to provide for ambulant hospice teams and networks, to ensure that palliative care be available at home, wherever ambulant care for the terminally ill or dying may be feasible;
• to ensure co-operation between all those involved in the care of a terminally ill or dying person;
• to ensure the development and implementation of quality standards for the care of the terminally ill or dying;
• to ensure that a terminally ill or dying person will receive adequate pain relief (unless the patient chooses otherwise) and palliative care, even if this treatment as a side-effect may contribute to the shortening of the individual's life;
• to ensure that health professionals be 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;
• 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;
• to ensure that specialised palliative care units as well as hospices be established at least in larger hospitals, from which palliative medicine and care are to evolve as an integral part of any medical treatment;
• to ensure that palliative medicine and care be 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

• 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;
• to enable any terminally ill or dying person to consult doctors other than his or her usual doctor;
• to ensure that no terminally ill or dying person be treated against his or her will while ensuring that the individual neither be influenced nor pressured by another person. Furthermore, safeguards are to ensure that this wish not be formed under economic pressure;
• to ensure that a currently incapacitated terminally ill or dying person's advance directive or living will refusing specific medical treatments be observed. Furthermore, by ensuring that criteria of validity as to the bearing of such advance directives as well as the nomination of proxies and the scope of their authority be defined;

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

• to ensure that in situations where an advance directive or living will does not exist the patient's right to life not be 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 taking the necessary measures

• to ensure that the right to life, especially with regard to a terminally ill or dying person, be 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...";

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

• to ensure that a terminally ill or dying person's wish to die never constitutes any legal justification to carry out actions intended to bring about death.

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 Health 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 cooperation 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 absorb 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.

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. 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 Haegh, Mrs Hornikova, Mrs Jirousova, Mr Kalos, Mrs Kubaka, Mrs Laternser, Mr Liv, 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, Sincal (Alternate: Mr Paslaru), Skoularikis, Mrs Stefani, MM. Surján (Alternate: Mr Kelemen), Tahir, Valkeniers, Veila, 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

Protection of the human rights and dignity of the terminally ill and dying

Doc. 8454

22 June 1999

Opinion (I)

Committee on Legal Affairs and Human Rights

Rapporteur: Mr Kevin McNamara, United Kingdom, Socialist Group

The general thrust of the report was welcomed by the Committee on Legal Affairs and Human Rights in its compassionate and considered attitude to the problems affecting the terminally ill and dying and the need for actual citizens and member governments to take all steps necessary to maintain the human dignity of fellow citizens who are terminally ill and dying. Paragraphs 1 to 9.b of the draft recommendation are uncontested and welcomed.

However an amendment (Amendment C) is proposed to sub-paragraph 9.c.iii because as it stands this sub-paragraph could be seen to be in contradiction to the following sub-paragraphs:

- sub-paragraph 9.b.iii ("to ensure that no terminally ill or dying person be treated against his or her will while ensuring that the individual neither be influenced nor pressurised by another person .;")
- sub-paragraph 9.b.iv ("to ensure that a currently incapacitated terminally ill or dying person's advanced directive or living will refusing specific medical treatments be observed .;")
- sub-paragraph 9.b.v ("to ensure that . expressed wishes of a terminally ill or dying person with regard to particular forms of treatment be taken into account, .").

Thus the substantive motion amendment to sub-paragraph 9.c.iii proposed by the Committee on Legal Affairs and Human Rights seeks to remedy the apparent contradiction existing in the original proposal whilst being in the spirit of the general thrust of the report and recommendation together with Article 2 § 1 of the European Convention on Human Rights which states that "Everyone's right to life shall be protected by law. No one should be deprived of his life intentionally .".

Amendments A and B are stylistic rather than substantive.

Proposed amendments to the draft recommendation

Amendment A

In sub-paragraph 9.c.i, first line, delete "to ensure" and insert "recognising that" and in the second line, delete the word "be" and insert the word "is", so that it reads:
"recognising that the right of 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 shall be deprived of his life intentionally."

Amendment B

In sub-paragraph 9.c.ii, first line, delete "to ensure" and insert "recognising" so that it reads:

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

Amendment C

In sub-paragraph 9.c.iii, delete "to ensure" and insert "recognising" and replace the words "never constitutes any" by the words "cannot of itself constitute", so that it reads:

"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".

Reporting committee: Social, Health and Family Affairs Committee

Committee for opinion: Committee on Legal Affairs and Human Rights

Reference to committee: Doc 7236, Reference No 1996 of 15 March 1995

Opinion approved by the committee on 22 June 1999

Secretaries to the committee: Mr Plate, Ms Coin and Ms Kleinsorge

Note: 1 See Doc 8421.

Quelle:
Recommendation 1418 (1999)¹

Protection of the human rights and dignity of the terminally ill and the dying

(Extract from the Official Gazette of the Council of Europe – June 1999)

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:

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

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

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

   iv. the lack of continuing education and psychological support for health-care professionals working in palliative medicine;
v. insufficient care and support for relatives and friends of terminally ill or dying patients, which otherwise could alleviate human suffering in its various dimensions;

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

vii. 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;

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

ix. 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:

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

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

   iii. dying alone and neglected;

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

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

   vi. 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:

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

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

      iii. 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;

      iv. 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;

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

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

      vii. 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;

      viii. 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;

      ix. 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;
x. 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;

xi. 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:

i. 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;

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

iii. 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;

iv. 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;

v. 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;

vi. 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:

i. 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”;

ii. 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;

iii. 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.

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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).

Quelle:
Protection of the human rights and dignity of the terminally ill and the dying

Doc. 8888

7 November 2000

Recommendation 1418 (1999)

Reply from the Committee of Ministers

adopted at the 728th meeting of the Ministers’ Deputies (30 October 2000)

The Committee of Ministers has carefully considered Parliamentary Assembly Recommendation 1418 (1999) on the protection of the human rights and dignity of the terminally ill and the dying and fully shares the Assembly’s concerns in this respect. The Recommendation raises highly complex problems, which the Committee of Ministers has already considered in various connections, including the 1981 European Health Committee (CDSP) report on care of the dying, the 1988 euthanasia discussions of the Ad Hoc Committee on Bioethics (CAHBI), and the work leading to adoption of the Convention on Human Rights and Biomedicine (the Bioethics Convention).

The Committee of Ministers notes that the Assembly asks it to “encourage the member states to respect and protect the dignity of terminally ill or dying persons in all respects”, particularly stressing, first, access to care, including palliative care; second, the terminally ill or dying person's right to self-determination; and, third, the prohibition on intentionally taking the life of a terminally ill or dying person.

The Committee of Ministers observes that the CDSP has selected the question of palliative care for a detailed study in 2001. The CDSP intends tackling the question in the wider context of the environment in which palliative care is delivered. The study will look at questions such as over-zealous medical prolongation of life, equal access to health care for old people, professional training in palliative care and reform of medical practice in hospitals and institutions.

As regards terminally ill or dying people's right to self-determination, the Committee of Ministers draws attention to Article 9 of the Bioethics Convention, which reads: “The previously expressed wishes relating to a medical intervention by a patient who is not, at the time of the intervention, in a state to express his or her wishes shall be taken into account.” It should be pointed out that this wording reflects the maximum convergence of views among states which took part in drawing up the convention as regards reconciling patient self-determination and medical responsibility.

With regard to the absolute prohibition on intentionally taking the life of a terminally ill or dying person, the Committee of Ministers notes that the legal position differs from one member state to another on advance refusal of certain treatments and on euthanasia. Therefore, with a view to obtaining an overview of laws and/or practices of member states with regard to the issues raised by the Recommendation, the Committee of Ministers instructed the Steering Committee on Bioethics (CDBI) to gather relevant information.
Furthermore the Committee of Ministers stresses that protection of the individual’s fundamental rights - including those of the ill or dying - is a matter for the member states, under the supervision, where appropriate, of the European Court of Human Rights. Consequently, the Committee of Ministers has also instructed the Steering Committee for Human Rights (CDDH) to formulate an opinion on Recommendation 1418 (1999).

Quelle:
Protection of the human rights and dignity of the terminally ill and the dying

Recommendation 1418 (1999)

Doc. 9404

8 April 2002

Reply from the Committee of Ministers

adopted at the 790th meeting of the Ministers’ Deputies (26 March 2002)

1. The Committee of Ministers welcomes the work carried out by the Parliamentary Assembly, leading to Recommendation 1418 (1999), which addresses the particularly sensitive issues of the protection of human rights and the dignity of the terminally ill and the dying. It recalls its interim reply, adopted on 30 October 2000, informing the Assembly of the terms of reference given to the Steering Committee for Human Rights (CDDH) and the Steering Committee on Bioethics (CDBI).

2. Having closely studied the resulting information and opinion, the Committee observes that member states have differing approaches to the issues dealt with in the recommendation. There are many aspects to these issues — particularly ethical, psychological and sociological aspects — but the Committee of Ministers, committed to the respect and protection of fundamental human rights, intends to restrict itself to the one incontestable area of Council of Europe competence: human rights protection under the European Convention on Human Rights and the case law of the European Court of Human Rights.

3. Certain issues raised by the recommendation go to the heart of the Convention, particularly regarding to Articles 2 (Right to life), 3 (Prohibition of torture and inhuman or degrading treatment or punishment), and 8 (Right to respect for private and family life). Since, as yet, there is no case law of the Court which could provide precise answers to all the questions raised in the Recommendation, the Committee prefers to limit itself to the following points.

4. First, under Article 1 of the Convention, the High Contracting Parties undertake to secure to everyone within their jurisdiction the rights and freedoms defined in the Convention. This is a binding obligation for all Parties, irrespective of any expression of will by the person concerned in this respect. Therefore, in the case of patients who are entirely incapable of self-determination, the Court has pointed out that they nevertheless remain under the protection of the Convention[1].

5. This must be borne in mind when considering the "right of the terminally ill or the dying to self-determination", referred to notably in paragraph 9 (b) of the Recommendation. The Committee of Ministers therefore welcomes in this respect paragraph 9 (c) of the Assembly Recommendation, to "encourage the member states of the Council of Europe to respect and protect the dignity of terminally ill or dying persons in all respects...by upholding the prohibition against intentionally taking the life of terminally ill or dying persons, while:
i. 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’;

ii. 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;

iii. 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.”

6. There can be no derogations from the right to life other than those mentioned under Article 2 of the Convention. Apart from these cases, no one may be intentionally deprived of life, as the Assembly notes in paragraph 9 (c)(i). The Court has not, however, yet had occasion to rule on the relevance of Article 2 to the proposals set out in paragraph 9 (c) (ii) and (iii).

7. As regards the protection of human dignity afforded by Article 3 (“no one shall be subjected to torture or to inhuman or degrading treatment or punishment”), its requirements permit of no derogation. It is true that the Court stated that “as a general rule, a measure which is a therapeutic necessity cannot be regarded as inhuman or degrading”, but it also noted that the assessment of an act as ill-treatment falling within the scope of Article 3 "depends on all the circumstances of the case, such as the duration of the treatment, its physical or mental effects and, in some cases, the sex, age and state of health of the victim, etc." Moreover, Article 3 includes a number of obligations for the state: “Children and other vulnerable individuals, in particular, are entitled to state protection, in the form of effective deterrence, against such serious breaches of personal integrity”.

8. The right to respect for private and family life, as guaranteed by Article 8, would become relevant in some instances, but there are only very rare examples of case-law from the Strasbourg organs that could be linked to questions relating to the dignity of the sick within the scope of such a provision.

9. The dual objective of alleviating suffering whilst avoiding such violations may give rise to a wide range of national measures. The recommendation draws attention to those concerning palliative care (see notably paragraph 9 (a)). Although definitions of palliative care do exist, the recommendation does not define these terms any more than it gives a definition of the concept of “pain management” mentioned in paragraph 7 (i) – rightly in the Committee’s view, as it does not seem possible to give a uniform European definition of such very broad concepts. The Committee refers in this context to the work being carried out on palliative care by the European Health Committee.

10. It follows, in the Committee of Ministers’ view, that several of the proposals made by the Parliamentary Assembly to member states, in particular a greater commitment on their part to relieving human suffering, can help protect human rights and the dignity of the terminally ill and the dying, provided that the articles of the European Convention on Human Rights mentioned in this reply are respected.

11. However, in the absence of precise case-law, the question of “human rights of the terminally ill and the dying”, seen from the angle of the Convention, gives rise to a series of other very complex questions of interpretation, such as:

- the question of interplay and possible conflict between the different relevant rights and freedoms and that of the margin of appreciation of the States Parties in finding solutions aiming to reconcile these rights and freedoms;

- the question of the nature and the scope of positive obligations incumbent upon States Parties and which are linked to the effective protection of rights and freedoms provided by the Convention;

- the question of whether the relevant provisions of the Convention must be interpreted as also guaranteeing “negative rights”, as the Court has ruled for certain Articles of the Convention, as well as the question of whether an individual can renounce the exercise of certain rights and freedoms in this context (and, if that is the case, in to what extent and under which conditions).

12. With regard to legislation and practices in member states concerning the problems addressed in the recommendation, the Steering Committee on Bioethics is working on a report, in accordance with the terms of reference assigned to it by the Committee of Ministers. This report, due to be finalised in the course of 2002, will be forwarded to the Assembly in due course. The CDDH, for its part, will follow the development of these issues attentively.

13. In addition, concerning issues related to palliative care, to which the Assembly devoted an important section of its recommendation, the European Health Committee (CDSP) has prepared a study of the situation in many European countries, taking particular account of the contribution made by the Eastern and Central European Task...
14. The Committee of Ministers wishes at this stage to inform the Assembly that the proposals contained in its Recommendation 1418 (1999) have broadly contributed to the deliberations carried out in this field. Furthermore, the Committee of Ministers welcomes the contacts established between the chairpersons of the competent sub-committee of the Assembly and the committee of experts on the organisation of palliative care.


[2] "(Article 2) not only safeguards the right to life but sets out the circumstances when the deprivation of life may be justified; Article 2 ranks as one of the most fundamental provisions in the Convention - indeed one which, in peacetime, admits of no derogation under Article 15. Together with Article 3 of the Convention, it also enshrines one of the basic values of the democratic societies making up the Council of Europe. As such, its provisions must be strictly construed", European Court of Human Rights, McCann and others v. the United Kingdom, 27 September 1995, §147.


[4] Ibid. The Court pointed out that it had to satisfy itself that this necessity had been convincingly shown to exist.


[6] European Court of Human Rights, A. v. the United Kingdom, 23 September 1998, § 22. States must consequently take legislative or other measures to ensure that individuals within their jurisdiction, especially the most vulnerable - which includes the terminally ill and the dying - are not subjected to inhuman or degrading treatments. Moreover, in a case involving very exceptional circumstances, the Court pointed out that the expulsion of a patient in the terminal phase of AIDS to a country where health conditions were unfavourable would constitute inhuman treatment, given that his expulsion would expose him to a real risk of dying in particularly painful circumstances; see European Court of Human Rights, D. v. the United Kingdom, 2 May 1997, Reports 1997/III, No. 37, §§53-54.


[8] The World Health Organisation defines 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” (quoted in the Parliamentary Assembly of the Council of Europe, Report on the Protection of the human rights and dignity of the terminally ill and the dying, Doc. 8421, 21 May 1999, by Ms Edeltraud Gatterer).

[9] This work is mentioned in the interim reply adopted by the Ministers' Deputies on 30 October 2000.

[10] For example, for Articles 9 and 11 of the Convention (respectively, the freedom not to have a religion and freedom not to associate with others). (See, for example, the European Court of Human Rights, Buscarini and others v San Marino, 18 February 1999, § 34, and European Court of Human Rights Sigurdur Sigurjonsson v. Iceland, 30 June 1993, § 35)