Parliamentary Assembly
Assemblée parlementaire
COUNCIL OF EUROPE CONSEIL DE L'EUROPE

Parliamentary **Assembly**
Assemblée parlementaire

Doc. 10455
9 February 2005

Assistance to patients at end of life

Report
Social, Health and Family Affairs Committee
Rapporteur: Mr Dick Marty, Switzerland, Liberal, Democratic and Reformers' Group

Summary

The Parliamentary Assembly recalls that assistance at the end of people's lives is a delicate issue to which everyone is sensitive and one that touches on the moral, religious and cultural values of our societies.

In accordance with the principle of respect for human rights and human dignity, the Assembly considers it imperative to introduce a proper policy for assisting people at the end of their lives which does not prompt them to want to die.

To this end, it proposes promoting palliative care, the widespread provision of care in patients' own homes and the avoidance of over-zealous prolongation of life.

The Assembly also draws attention to the need for a clear definition both of patients' rights and of the tasks and responsibilities of the medical profession and nursing staff.

The Assembly proposes, with due regard for cultural and religious diversity in member states, fostering public debate on this issue.

F – 67075 Strasbourg Cedex, tel: +33 3 88 41 20 00, fax: +33 3 88 41 27 97, http://assembly.coe.int, e-mail: assembly@coe.int

I. Draft resolution

1. The Parliamentary Assembly pointed out in its Recommendation 1418 (1999) on protecting the human rights and dignity of the terminally ill and the dying that "the vocation of the Council of Europe is to protect the dignity of all human beings and the rights which stem therefrom". Consequently, when the problem of assisting patients at the end of their lives is addressed, it is important and necessary to reaffirm this fundamental principle forcefully. The Assembly takes this opportunity to reiterate its unwavering belief that this principle means, inter alia, that it is forbidden to cause someone's death deliberately.

2. The question of assisting patients at the end of life remains, however, and the Assembly cannot ignore the following facts:

i. two Council of Europe member states, the Netherlands and Belgium, have passed laws that specifically address the issue of euthanasia;

ii. in numerous other countries, bills with a view to legislation in this field have been tabled or even discussed in parliament;

iii. opinion polls, particularly those carried out in the wake of high-profile cases, show that people are highly sensitive to this issue and in several countries there seems to be a majority in favour of euthanasia, at least in a limited number of very special cases;

iv. some serious scientific studies clearly show that various forms of euthanasia are practised in hospitals in several countries without any specific regulations or in spite of a formal prohibition of the practice, in proportions well in excess of what was previously believed.

3. The Assembly is perfectly aware that this is a very delicate issue to which everybody is sensitive and touches on the moral, religious and cultural values of our societies. It follows that the approach to the problem and the solutions we seek cannot be the same for all countries. It is essential that we respect these different sensitivities, while reiterating the inviolable principle that human rights and dignity must be respected.

4. Member states of the Council of Europe should define and implement a genuine policy of assistance to patients at the end of life which does not cause them to want to die. The following measures should therefore be taken or, if they already exist, be enhanced:

i. the promotion of palliative treatment, bearing in mind that the aim is to alleviate the patient's suffering, while also realising that it may shorten his or her life in certain cases;

ii. the establishment of appropriate health-care arrangements for the terminally ill, with specially trained staff;

iii. the widespread provision of care in patients' own homes and inclusion of their family and close friends in the end-of-life assistance;

iv. the development of codes of medical ethics to avoid superfluous treatments which can be regarded as over-zealous prolongation of life;

v. the promotion or the reinforcement of a genuine suicide prevention policy.

5. In order to achieve greater transparency and to reduce as far as possible the practice of euthanasia in secret or in a legal vacuum, as highlighted by recent studies, it appears necessary to strengthen the patient's position and to define clearly the tasks and responsibilities of medical and nursing staff. The patients concerned are often in a highly vulnerable situation and their rights should therefore be clearly established and effective machinery put in place to guarantee the exercise of and full respect for those rights. It is important that every patient see recognised:

i. the right of any patient who so requests to be properly informed as promptly as possible of his or her condition, the treatment administered and the chances of success and the risks involved;

ii. the right of any patient capable of discernment, being fully aware of the facts, to decline the treatment proposed;

iii. an effort to determine the presumed wishes of patients who are no longer able to express their wishes, including either through the preparation of "living wills" or through the appointment of a representative mandated by the patient to deal with medical questions ("representative for medical matters");

iv. the right to obtain rapidly an independent second medical opinion;

v. the creation of an independent body with which patients, families or their legal representatives can register complaints;

vi. the introduction, where they do not yet exist, of procedures and provisions clearly defining the responsibilities of medical and nursing staff and ensuring the traceability of all decisions and measures taken, thus facilitating effective monitoring;

6. The Assembly, being perfectly well aware that in the current situation and in view of the diversity of cultural and religious sensitivities in the member States, it is hardly possible to recommend a universal model for all to follow, nevertheless recommends that member States of the Council of Europe should:

i. analyse objectively and in depth the experience with the legislation introduced in the Netherlands and Belgium and the bills on the subject currently being discussed in other countries;

ii. take the necessary steps to recognise and guarantee specific rights for patients at the end of life, i.e. right to information, patient consent, representatives for medical matters, collegiate decisions by the medical profession, traceability of decisions and the right to decide what to do with one's person;

iii. set up or, if they exist already, reinforce palliative care units and, as far as possible, home care and other appropriate health facilities for the terminally ill;

iv. promote or consolidate a comprehensive suicide prevention policy;

v. prevent euthanasia from developing in a shroud of secrecy because of legal uncertainties or outdated norms;

vi. accurately define the responsibilities and procedures for discontinuing treatment where it will only secure a slight prolongation of life without any hope of survival and inflict unnecessary additional suffering on the patient;

vii. promote public discussion so as to create the greatest possible transparency and accountability in an area too often subject to decisions taken by the medical and paramedical profession without any form of control;

viii. pay particular attention to ensuring that the current social changes in many countries in Europe, such as the ageing of the population and increasing health costs, do not give rise to social or family pressure to seek assistance with suicide or to request euthanasia, undermining society's feeling of responsibility towards elderly and dependent persons.

II. Explanatory memorandum by Mr Marty

Table of contents

II. Explanatory memorandum by Mr Marty

1. Introduction 4

2. Preliminary remarks 5

3. Definitions 6

4. Recommendation 1418 (199) and the Committee of Ministers' replies 6

5. Empirical evidence regarding decisions to terminate life 8

6. Criticisms levelled at euthanasia and the new legislation in the Netherlands and Belgium (see appendices 1 and 2) 9

7. Arguments in favour of partial decriminalisation of euthanasia 10

8. Conclusions 11

Appendix 1 – The new legislation in the Netherlands 13

Appendix 2 – The new Belgian legislation 14

Appendix 3 –Swiss law 17

Appendix 4 – French bill on assistance to the end of life 18

1. Introduction

1. Following the adoption of Recommendation 1418 (1999) on the protection of the human rights and dignity of the terminally-ill and the dying, and in the light of new developments in some of the member countries of the Council of Europe, the Social, Health and Family Affairs Committee started to consider the extremely complex issue of euthanasia in September 2001 (Origin: Doc. 9170 presented by Mr Monfils, Belgium, LDR, and others, Ref. No. 2648, 25.09.01).

2. The Committee held a hearing on the various aspects of this subject with the participation of numerous experts at its meeting on 25 October 2002, in Paris (AS/Soc/Inf (2002) 2). Following this hearing, it considered a memorandum on 3 April 2003 and a preliminary draft report on 26 June 2003. Further to an intense debate and with a narrow majority it adopted a draft resolution on 5 September 2003 in Paris (AS/Soc (2003) PV 7).

3. On 1 March 2004, after an initial postponement of the debate, which had originally been scheduled for January, the Bureau of the Assembly decided once again to include this subject in the order of business for the second part-session in April 2004. At its meeting on 25 March 2004, at the suggestion of the Rapporteur, Mr Marty, the committee decided to ask the Assembly to hold a general debate without vote in plenary session, and subsequently to refer the report back to committee in order to continue discussions (AS/Soc (2004) PV 2). In his letter to the Bureau of the Assembly the Committee Chairperson, Mr Glesener, pointed out that this decision would enable the committee and rapporteur to fuel the debate on this highly complex and controversial subject, thus ultimately providing the Assembly with a more complete report.

4. The discussion was held on Tuesday 27 April 2004 in plenary session, during the Assembly's second part-session. In accordance with the proposal put forward by the Social, Health and Family Affairs Committee and the Bureau of the Assembly, the Assembly decided to refer the report back to the committee for additional examination and possible preparation of a new report within one year.

5. At its meeting in June 2004, the Committee endorsed the Rapporteur's proposal to change the title of the report and renew Mr Marty's mandate. A first preliminary draft report was discussed at the 7 October 2004 sitting.

2. Preliminary remarks

6. Euthanasia is an extremely complex issue that arouses intense emotions. The subject in fact lies at the crossroads between life and death, free will and religious belief, and therapy and medical intervention to bring about death. The reason why we find it so uncomfortable to address the issue is that it forces us to face up to the end of our own lives. So why are we having to discuss it again four years after the Parliamentary Assembly adopted Recommendation 1418 (1999) on protection of the human rights and dignity of the terminally ill and the dying?

7. Every survey confirms that euthanasia is practised in many countries, in proportions well in excess of what was previously believed. But the fact is that euthanasia is a criminal offence in virtually every single country, which forces us to conclude that there is a striking divergence between the law and actual practice. Penal and professional sanctions are extremely rare by comparison with the number of presumed cases, in the light of the various surveys carried out.

8. Euthanasia may take different forms: a piece of equipment may be turned off, treatment may deliberately be withheld, or such a large dose of a therapeutic product may be administered that it causes or hastens the patient's death. Life may be terminated at the patients' or their family's request. Should the law intervene in what has been called "the final freedom"[1], and if so how?

9. Despite all the progress in the medical field, no answers have been forthcoming from this area. On the contrary, the latest medical techniques are making the problem even more acute.

10. There is one more important reason for addressing the issue of euthanasia: two Council of Europe member states, the Netherlands and Belgium, have recently adopted legislation which in a way poses a serious challenge to the other States and to this Parliamentary Assembly. This new situation obliges us to face up to the problems arising at the end of life, and particularly the issue of euthanasia.

11. Euthanasia is held by its opponents to be contrary to the European Convention on Human Rights, in particular Article 2 on the right to life. But in fact, the European Court of Human Rights has never tested this proposition[2]. On the other hand, the Belgian *Conseil d'Etat* and the Dutch Council of State have held that euthanasia as included in their national legislation is compatible with the Convention.

12. Lastly, public opinion polls in several member states show that a majority are in favour of legislation to regulate euthanasia, at least in certain cases and under very specific conditions[3]. We as politicians and legislators must somehow respond to this challenge. In any case, the silence in which this issue is more often than not enshrouded is evidently the worst approach.

---

[1] François de Closets, *La dernière liberté*, Paris, Fayard, 2000.

[2] Stéphanie Berthomé, Compatibilité de la législation sur l'euthanasie avec l'article 2 de la Convention européenne des Droits de l'Homme (Council of Europe, 1 December 2003, unpublished).

[3] For instance, according to a survey published in autumn 2003 in France, 86% of the French population are in favour of a law permitting doctors to end the lives of persons suffering from painful, irreversible diseases who have requested such measures, while 12% are against such legislation. Source: *L'opinion en question: l'euthanasie,* 23.10.2003 – Survey conducted for *Profession Politique*, published in *Profession Politique et Métro*, transmitted on LCP, www.bva.fr.

3. Definitions

13. To avoid any confusion, it is important to be clear about what we mean by the term "euthanasia". Etymologically, it means "a good death". In this report it will be used to mean *any medical act intended to end a patient's life at his or her persistent, carefully considered and voluntary request in order to relieve unbearable suffering.* This corresponds to what is generally referred to as "voluntary active euthanasia".

14. However, when discussing this issue, reference is sometimes made to the requires that we distinguish this concepts of from "non-voluntary active euthanasia", where the patient's consent is either impossible to obtain, perhaps because he or she is unconscious, or simply has not been obtained; and "involuntary active euthanasia", sometimes used to describe an act performed *against* the wish of the patient. It follows from the definition in paragraph 8 that such cases do not correspond to euthanasia.

15. "Passive euthanasia" is a term used to mean the withholding or withdrawal of life-sustaining treatment, again with the intention of ending it, in particular where the alternative is to attempt to keep the patient alive through stubborn, aggressive and pointless treatment, a practice condemned in medical ethics, not least when the patient has refused such treatment. Finally, "physician-assisted suicide" covers situations where a doctor helps a patient to take his or her own life, again at his or her persistent, carefully considered and voluntary request.[4]

16. The discussions soon highlighted the fact that the focus could not be exclusively on the euthanasia concept. Firstly, the word itself is excessively laden with sombre overtones that conjure up sinister visions, if only because of its veterinary connotations and the abominable use made of it in some very dark periods of our history. The German word "Sterbehilfe" is clearly preferable, but it does not translate easily into other languages, nor is it very accurate because it can cover both euthanasia and helping a person to commit suicide, two very different physical acts and legal concepts. Secondly, the question must be considered in the wider and less ambiguous context of assistance to patients at the end of life. But what does "patients at the end of life" actually mean? The Swiss Academy of Medical Sciences proposes the following definition in a set of draft medico-ethical guidelines on "provision for patients at the end of life": "patients for whom the physician, on the basis of the clinical indications, has acquired the conviction that a process has set in which medical professionals know from experience will lead to death within a number of days or weeks"[5].

4. Recommendation 1418 (1999) and the Committee of Ministers' replies

17. Recommendation 1418 (1999) first observed that the terminally ill and the dying lacked adequate access to palliative care and good pain management. The Assembly therefore encouraged the member states to promote comprehensive palliative care through a series of constructive measures such as the establishment of more palliative care units in hospitals, the development of hospices and ambulant hospice teams and networks, and specific training for health professionals. The Committee of Ministers replied (Doc. 8888) that the European Health Committee had selected the question of palliative care for detailed study. This was certainly a welcome outcome and we look forward to the results which are due to be published shortly.

18. Recommendation 1418 also asked the member states to protect the terminally ill or dying person's "right to self-determination". But this did not include the right to choose the timing and manner of one's own death. What was meant was spelt out in the accompanying guidelines relating to the patient's rights: to be truthfully and comprehensively informed (or not to be informed) about one's condition; to consult other doctors; not to be treated against one's will, while being protected from undue pressures; to have one's "advance directive" or "living will" observed under specified conditions if incapacitated; to have one's wishes as to specific treatment taken into account as far as possible;

---

[4] The recent survey on euthanasia conducted by Dr Michael Abrams for the Council of Europe's Steering Committee on Bioethics (CDBI) provides interesting information on, among other things, definitions used in the member states, including legal definitions (see *http://www.coe.int/T/E/Legal_Affairs/Legal_co-operation/Bioethics/Activities/Euthanasia/*).

[5] See http:/www.samw.ch/

and to have one's right to life respected in the absence of a "living will". In view of the importance of the guidelines and the fact that they are not yet being fully implemented, it seemed useful to repeat some of them.

19. On the issue of whether the "living will" must be respected, the Committee of Ministers noted (Doc. 9404) that the wording of Article 9 of the Council of Europe's Convention on Human Rights and Biomedicine ("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.") reflected the "maximum convergence of views", at the time of drafting, "as regards patient self-determination and medical responsibility".

20. Finally, Recommendation 1418 asked the member states to uphold 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."

21. In its replies, the Committee of Ministers noted that the legal position on advance refusal of certain treatments and on euthanasia differed between member states. The Committee of Ministers therefore asked its Steering Committee on Bioethics (CDBI) to undertake a survey of their relevant laws and practices. This work has been published (cf. footnote 2). The expert who conducted the survey also wrote an accompanying report, which the CDBI has not made public. Since it was hardly discussed in the CDBI, the expert's report should be published.

22. In connection with Article 2 of the European Convention on Human Rights (right to life), the Committee of Ministers replied that its relevance to euthanasia had never been tested.

23. Furthermore, the Committee of Ministers discussed other aspects raised by Articles 3 and 8 ECHR and acknowledged that "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 interaction 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)."[6]

24. The Court's position on the issue of whether the right to life implies its negative was clarified in its judgement in the case of Diane Pretty, whereby "Article 2 cannot, without a distortion of language, be interpreted as conferring the diametrically opposite right, namely a right to die; nor can it create a right to self-determination in the sense of conferring on an individual the entitlement to choose death rather than life. ... The Court accordingly finds that no right to die, whether at the hands of a third person or with the assistance of a public authority, can be derived from Article 2 of the Convention".[7]

---

[6] Doc. 9404

[7] *Pretty v. the United Kingdom*, 29 April 2002, §§ 39-40.

It nevertheless remains that the Court has not tested the proposition that euthanasia is contrary to the Convention. However, the Council of State in both the Netherlands and Belgium have concluded that the legislation on euthanasia introduced in those countries is compatible with the Convention (see Appendices 1 & 2).

5. Empirical evidence regarding decisions to terminate life

25. Empirical data on the rate of euthanasia, physician-assisted suicide, and other end–of-life decisions have greatly contributed to the debate about the role of such practices in modern healthcare.

26. There have been few large-scale empirical studies in Europe. The best known relate to the Netherlands and Belgium (Flanders). In 1990-1991 a survey of euthanasia and other end-of-life practices in the Netherlands, the first of its kind in a single country, was commissioned by a governmental committee chaired by the Attorney General of the Dutch Supreme Court, Professor Jan Remmelink. A second, almost identical, survey was carried out in 1995-1996, commissioned by the Ministers of Health and Justice, in order to evaluate the new procedure for reporting physician-assisted deaths that had been introduced in 1991. Both surveys were based on two parallel investigations: one involving *interviews* with a random sample of doctors, the other involving *questionnaires* addressed to doctors who had assisted deaths identified from a random sample of death certificates.

27. Among the deaths studied in the 1995 survey, 2.3 % of those in the interview study and 2.4 % of those in the death certificate study were estimated to have resulted from euthanasia, as opposed to 1.9 % and 1.7 % respectively in the 1990 survey. The increases were explained by the new reporting procedure introduced in 1991. In 1995, 0.4 % (interview study) and 0.2 % (death certificate study) resulted from physician-assisted suicide (1990 = 0.3 % and 0.2 %, respectively). The 1995 survey found, in both interview and death certificate studies, that in 0.7 % of cases, life was ended without the explicit, concurrent request of the patient. In 1990 this figure was not available for the interview study but yielded 0.8 % in the death certificate study.

28. Results from both surveys showed that in 14.7 to 19.1 % of cases, pain and symptoms were alleviated with doses of opioids that may have shortened life. Decisions to withhold or withdraw life-prolonging treatment were made in 20.2 % of cases in 1995 over 17.9 % in 1990 (death certificate study only). For each type of medical decision except those in which life-prolonging treatment was withheld or withdrawn, cancer was the most frequently reported diagnosis.

29. The 1995 survey concluded that since the notification procedure had been introduced in 1991, end-of-life decision-making in the Netherlands had changed only slightly, in anticipated directions: euthanasia seemed to increase in incidence, and the ending of life without the patient's explicit request seemed to decrease slightly. Close monitoring of such decisions was possible, and no signs of an unacceptable increase in the number of decisions or of less careful decision making were found, according to the authors.[8]

30. The continuing debate about whether and when physician-assisted dying is acceptable seems to be resulting in a gradual stabilisation of end-of-life practices. The 1990 and 1995 interview and death-certificate studies have been renewed more recently, showing that no further increase in the rate of euthanasia was found in 2001[9].

31. A comparable survey was conducted in 1998 in Flanders, Belgium, based on a random sample of death certificates and questionnaires to the attending physicians. Of the 4.4 % of all deaths resulting from the use of lethal drugs, 1.1 % were cases of euthanasia, 0.1 % physician-assisted

[8] Paul J. van der Maas, M.D., Ph.D., Gerrit van der Wal, M.D., Ph.D., Ilinka Haverkate, M.Sc., Carmen L.M. de Graaff, M.A., John G.C. Kester, M.A., Bregje D. Onwuteaka-Philipsen, M.Sc., Agnes van der Heide, M.D., Ph.D., Jacqueline M. Bosma, M.D., LL.M., and Dick L. Willems, M.D., Ph.D., "Euthanasia, Physician-Assisted Suicide, and Other Medical Practices Involving the End of Life in the Netherlands, 1990–1995", *The New England Journal of Medicine*, **335**:1699-1705 (November 28), 1996.

[9] "Euthanasia and other end-of-life decisions in the Netherlands in 1990, 1995 and 2001", the Lancet, 17 June 2003

suicide, and 3.2 % ending of life without the patient's explicit request (extrapolated to an estimated total of 1 796 cases in 1998). In 18.5 % of patients, high-dose opioids were used to alleviate pain and resulted in unintentional death in 13.2 % of cases, but in intentional death in 5.3 % of cases. Decisions to withhold or withdraw potentially life-prolonging treatment were made in 16.4 % of cases.[10]

32. Comparing their results internationally, the authors concluded that "in Flanders the rate of administration of lethal drugs to patients without their explicit request is similar to Australia, and significantly higher than that in the Netherlands". This might be due, they surmised, to the open and regulated approach then already prevalent in the Netherlands.

33. Evidence given at the Social, Health and Family Affairs Committee's hearing on euthanasia (Paris, 25 October 2002) revealed that in the United Kingdom almost 60 % of doctors questioned by the *British Medical Journal* had said they had been asked to hasten death; 32 % said they had complied with such a request; and 46 % said they would consider helping someone to die if it were legal to do so.[11] In a 1998 survey carried out by *The Sunday Times*, 14 % of the doctors who answered admitted that they had helped a patient to die at their request. A survey carried out in Norway in 1997 revealed that there were some 20 cases per year.

34. The most recent, and probably the fullest survey to date was published in summer 2003, covering six European countries (Belgium, Denmark, Italy, Netherlands, Sweden and Switzerland)[12]. The researchers considered three types of assistance at the end of life, namely the rejection of aggressive medical treatment, pain relief and euthanasia (including medically assisted suicide). A surprising number of deaths due to medical decisions was noted[13]. While active euthanasia at the patient's express request would appear to be in the statistical minority, when we compare it with the other causes of death it is nevertheless regularly practised, even in countries where it is prohibited (which represent the great majority). Criminal convictions and administrative and professional sanctions are, on the other hand, extremely rare. These facts cannot be a matter of indifference to our politicians.

35. These brief glimpses of medical reality are substantiated by our reading of the daily press. Anecdotal evidence abounds, and doctors in many countries admit that they have carried out euthanasia. It may be concluded that there is an urgent need for more scientific research, whatever its limitations, on this important subject. We are shocked by this mismatch between reality and the legal system because it is contrary to the elementary principles of democracy and the rule of law.

6. Criticisms levelled at euthanasia and the new legislation in the Netherlands and Belgium (see appendices 1 and 2)

36. The principal arguments against euthanasia and its decriminalisation are, first of all, that euthanasia is deemed to be incompatible with the fundamental human right to life and the concept of human dignity from which it stems. This is the whole thrust of the argument underlying Recommendation 1418 (1999). Prohibition on intentionally causing death is a cornerstone of all social relations, emphasising our fundamental equality. Therefore euthanasia remains a criminal offence in all Council of Europe member states, save under specified conditions in the Netherlands and Belgium. Moreover, it would be contradictory, or at least perverse, to work for abolition of the death penalty and at the same time for acceptance of euthanasia.

---

[10] Luc Deliens, Freddy Mortier, Johan Bilsen, Marc Cosyns, Robert Vander Stichele, Johan Vanoverloop, Koen Ingels, "End-of-life decisions in medical practice in Flanders, Belgium: a nationwide survey", *The Lancet*, **356**: 1806-11 (November 25), 2000.

[11] Ward, B.J. Tate, P.A. "Attitudes among NHS doctors to requests for euthanasia" *British Medical Journal*, **308**: 1332-1334 (1994)

[12] Agnes van der Heide et al., "Medical end-of-life decision-making in six European countries", The Lancet, Vol. 361, 2 August 2003.

[13] The French newspaper *Le Monde* published a report on this survey under the following title: *Over one-quarter of all deaths in Europe allegedly due to medical decisions* (*Le Monde*, 7 August 2003).

37. It is argued that euthanasia is contrary to the will of God as expressed in the Commandment: "Thou shalt not kill". For those unwilling to introduce divine authority into the discussion, it is contrary to medical ethics, including the Roman axiom "primum non nocere" ("first of all do not harm") and the Hippocratic Oath.

38. Opponents also point out that the relationship of confidence that must prevail between doctor and patient would be undermined by the former's power legally to end the latter's life. Moreover, most doctors have received no training in terminating life.

39. Those opposing euthanasia say that terminally ill and dying patients may be suffering not only physically but also mentally, in particular from depression, in which case their decision to ask for euthanasia may not be rational.

40. Finally, from both a logical and a practical point of view, it is said that it is impossible to provide a framework for voluntary euthanasia that will prevent abuse. Pressure may be exerted on the doctor to end the patient's life on non-medical grounds, including lack of hospital beds, the prospect of financial gain, or even political reasons. There will inevitably be a slide down the "slippery slope" from voluntary to involuntary and non-voluntary euthanasia. People will be killed who never asked to die and who could have been helped by palliative care. Indeed, the development of palliative care will make euthanasia unnecessary.

7. Arguments in favour of partial decriminalisation of euthanasia

41. The main arguments for euthanasia and its decriminalisation relate first of all to self-determination or personal autonomy: each individual, out of respect for his or her dignity and value, has a right to take decisions concerning his or her own life and death in accordance with his or her own values and beliefs, and not to have these imposed. It is a question of freedom and equality in the face of death. Similarly, this right does not imply an obligation on any health worker to take part in an act of euthanasia. In such matters, freedom of conscience and respect for free, conscious choices should prevail.

42. Advocates of euthanasia argue that, nobody has the right to impose on the terminally-ill and the dying the obligation to live out their life in unbearable suffering and anguish where they themselves have persistently expressed the wish to end it. Doctors have long accepted exceptions to the precepts of medical ethics, in carrying out abortions for example. Abortion itself has been legal for many years.

43. There has been a similar change of social attitudes to suicide, once considered a criminal offence by civil authorities and a sin by the Church, which in such cases used to refuse access to its cemeteries. Now we respect a person's choice to take their own life and avoid making value judgements about them.

44. Whereas palliative care is absolutely essential in attempting to ease the pain of the terminally ill and the dying, unfortunately some patients find it inadequate. Palliative care cannot in all circumstances take away unbearable pain and suffering. In any case the issue goes beyond the alleviation of pain: the degree of patients' their suffering, including mental anguish and loss of dignity, is something that only they can assess. Individuals suffering in the same situation may take different end-of-life decisions, but each human being's choice is deserving of respect. Depression should not come into it, to the extent that the doctor treating the patient has got to know the case, and the request for euthanasia has been persistently expressed.

45. The fact that the Council of Europe favours abolition of the death penalty is not inconsistent with favouring euthanasia, since the former, barring the exception that proves the rule, is carried out against the will of the individual concerned.

46. Since "passive euthanasia" – withdrawing life-sustaining treatment or means of support in the knowledge that death will result (an act of commission if ever there was one) – has been declared admissible in ethical, legal and religious[14] terms, it is difficult to see the moral distinction between this and active euthanasia.

47. Finally, euthanasia appears to be extensively practised in secret, or in an unacceptably and dangerously unclear legal context. It is precisely this mismatch between the affirmed principles and the reality that carries the greatest potential for abuse. Decisions may be taken in a furtive and arbitrary manner. They may depend on chance, the "luck of the draw": a sympathetic doctor or a malevolent nurse. The pressures that can influence end-of-life decisions will be more pernicious if exercised far from scrutinising eyes, from any form of supervision, such as that used in the Netherlands and Belgium. Obviously, abuse will not disappear with legislation (does any legislation eliminate abuse?), but it will certainly be considerably reduced.

8. Conclusions

48. The debate on euthanasia is, very understandably, highly emotionally charged. Few other subjects face us with such important and different, or indeed (apparently) opposing sets of moral and legal values. The horrors historically bound up with this concept give rise to natural suspicion and, in some people, complete rejection or an outright refusal even to discuss the subject. We consider it the duty of all politicians, operators in the community at large and legislators to tackle the problem, for there is indeed a problem, and it would be hypocritical to deny it. The incredible progress in medicine, the development of medical technology and the evolution in pharmaceutical products have helped, and are helping, to prolong life. This has all been an undeniable success. However, while the implementation of these resources can often put off the moment of death, this is sometimes achieved at the cost of great suffering, turning the end of life into a veritable ordeal. This prompts some individuals, in the name of their own conception of their personal human dignity and free will, lucidly and seriously to express their desire to die. Should we continue to disregard their choice? Should we continue to treat as criminals those who, driven by genuine feelings of compassion and solidarity, have helped such individuals to implement their wishes? Above all, should we continue to ignore a matter of common knowledge, namely the fact that euthanasia is regularly practised more or less all over the world without any proper supervision, in a hypocritical legal vacuum unworthy of the law-based State[15]?

49. The answers to these questions should not necessarily lead to the introduction of a right to or the decriminalisation of euthanasia. Cultural and religious differences in Europe are far too great for our Assembly immediately to envisage any single solution applicable to everyone[16]. It is nevertheless vital that we discuss it openly without casting serious aspersions on each other, as too often happens, including the last time we discussed the issue in plenary session. We have endeavoured to demonstrate our view that the discussion should not concentrate exclusively on euthanasia in the narrow meaning of the term. We must look into all the end-of-life issues, including the effective exercise and protection of the patient's rights, research into and implementation of palliative treatment, setting up of specialist institutions with appropriately trained staff, respect in all circumstances for the patient's dignity and freedom to choose the manner of his/her death, and the

---

[14] Including the Roman Catholic Church: Catechism No. 2279, recently quoted by the Swiss Bishop, who add the following comments: "Pope Pius XII taught that the physician's constant duty is to relieve a dying person's suffering, even at the risk of shortening his or her life. The policy to be followed is dictated by the fundamental ethical principle of safeguarding the dignity of the dying person. This applies to cases where the physician, without attempting to provoke death, endeavours to relieve a dying person's suffering with palliative treatment whose foreseeable effects will bring about death" (*Mourir dans la dignité,* Pastoral letter from the Swiss Bishops on euthanasia and support for the dying, 2002).

[15] In a recent interview, the French Health Minister said that 150 000 machines were switched off per year under medical decisions, which were not taken within any formal framework, and that an end had to be put to this "unacceptable hypocrisy"; lemonde.fr, 27 August 2004.

[16] On the matter of existing cultural differences on these issues, an interesting article was published in the NZZ (Neue Zürcher Zeitung) on 17 September 2003 entitled *Nord-Sud Gefälle bei ärztlichen Entscheidungen am Lebensende – Bei der Urteilsfindung spielt der kulturelle Hintergrund eine wichtige Rolle* (North-South divide as regards end of life medical decisions : the importance of cultural background).

[17] See eg Michel Dreyfus-Schmidt (Senator, member of the PACE), legalisation of euthanasia : the right solution, le Monde, 8 November 2003.

safeguarding of the professional status of medical and nursing staff and their freedom of conscience. The long-averted, indeed long-repressed debate has now been launched in many countries. Members of parliament well-known for their commitment to human rights have written pieces openly referring to decriminalising euthanasia, though naturally under very specific conditions[17]. In Luxembourg a bill to decriminalise euthanasia under certain conditions was rejected by only one vote[18]. In Italy too, the issue crops up at regular intervals[19]. The Council of Europe has also recently published a major work on this problem[20].

50. The French National Assembly has recently discussed a bill on end-of-life issues and patients' rights (see Appendix 4). This law will enable patients with a terminal illness to refuse treatment and allow doctors to discontinue superfluous or disproportionate medical procedures and alleviate the suffering of terminally ill patients by administering treatment which may have the side-effect of shortening their lives, provided that patients are informed of the potential consequences. It will also recognise the validity of instructions given in advance, through which patients may indicate their wishes in advance about reduction or discontinuation of treatment at the end of their lives, and, lastly, it will tighten up the legislation on palliative care[21]

51. The Netherlands and Belgium, after a long in-depth debate, thus decided that the time had come to legislate in this field and that certain forms of direct active euthanasia could be accepted, under very specific conditions and following a transparent, rigorous procedure. It we take the trouble to read these provisions and consider the discussions that preceded them, we cannot fail to notice how keenly aware the Belgian and Dutch legislators were of the issues at stake and how meticulously they took account of both the expediency of, and the risks involved in, legislating in such a sensitive, controversial area. Past, present and future experience of implementing these provisions will be important not only for the Netherlands and Belgium but also for the whole of Europe. The initial indications would not seem to point to any increase in the number of cases of euthanasia or any other types of abuse. Both these countries have an extraordinary humanistic heritage and a long tradition of respect for human life. They are both in the vanguard of medicine and assistance for the elderly. Will we, can we seriously contend that by partially decriminalising euthanasia the parliaments of these two countries are treating human life with contempt or indifference, or are indeed guilty of grave neglect in their duty to protect such life?

---

[18] N° 4934 Chambre des Députés : rapport de la Commission Spéciale "Ethique". Débat d'orientation sur la médecine palliative, l'acharnement thérapeutique et l'euthanasie. (Report of the Ethics Special Committee. Guidelines debate on palliative care).

[19] The former Health Minister and world-famous cancer specialist, Mr Umberto Veronesi, made the following statement in La Repubblica on 18 June 2000 : "Speaking as a minister, I feel there is no doubt that the law as it stands does not permit the practice of euthanasia. Speaking as a doctor, whose first duty is to save human lives and also to ensure death with dignity, the decisions are more complex. Speaking as a citizen, I recognise that as a large part of the population is for the practice of euthanasia, we should, without a referendum, be able to open a debate within the appropriate bodies, firstly through the National Committee on Bioethics and then in Parliament".

[20] Various authors, « Ethical Eye : Euthanasia – Volume I, Ethical and Human aspects » (2003), Volume II « National and European Perspectives » (2004), Council of Europe publishing.

[21] The bill was preceded by a thorough study : Mr Jean Leonetti (Chairman), Respect life - Accept death (Report n. 1708 on behalf of the French National Assembly's fact-finding commission on assistance at end of life), National Assembly, July 2004. Nevertheless other motions have been tabled clearly linked to euthanasia : Henriette Martinez, a bill on assistance on free choice concerning end of life, National Assembly n. 1395, 4 February 2004 and Michel Dreyfus-Schmidt (and the members of the Socialist Group and related), a bill on the right to benefit from euthanasia, Senate, n. 26, 14 October 2004. Moreover, the French Senate published in series "The Senate Documents : compared legislation": The rights of patients at end of life, n. LC 139, November 2004.

Appendix 1

The new legislation in the Netherlands

1. The "Termination of Life on Request and Assisted Suicide (Review Procedures) Act" which came into effect in the Netherlands on 1 April 2002, regulates statutorily and refines policy and practice on euthanasia developed over the previous thirty odd years. The Act built on the findings of State Commissions, scientific studies, public and parliamentary debates and, in particular, case law developed by the courts and accepted by the Government and the Parliament as guidance for prosecution policy in the matter.

2. Essentially, the new Act incorporates an amendment to Article 293 of the Criminal Code to the effect that although any person who terminates another person's life at that person's express and earnest request remains liable to a term of imprisonment not exceeding twelve years or a fifth category fine, such an act shall not be an offence if it is committed by a physician who notifies the municipal pathologist of this act in accordance with the relevant legislation and fulfils the stipulated due care criteria, by which the attending physician must:

a. be satisfied that the patient has made a voluntary and carefully considered request;

b. be satisfied that the patient's suffering is unbearable, and that there is no prospect of improvement;

c. have informed the patient about his situation and his prospects;

d. have come to the conclusion, together with the patient, that there is no reasonable alternative in the light of the patient's situation;

e. have consulted at least one other, independent physician, who must have seen the patient and given a written opinion on the due care criteria referred to in a. to d. above; and

f. have terminated the patient's life or provided assistance with suicide with due medical care and attention.

3. Similarly, any person who intentionally incites another to commit suicide, if suicide follows, is normally punishable under Article 294 the Criminal Code by a term of imprisonment not exceeding three years or a fourth category fine, but commits no offence if the above due care criteria are fulfilled.

4. The new legislation also includes regulations regarding termination of life on request and assisted suicide involving minors. It is generally assumed that minors too have the discernment to arrive at a sound and well-considered request to end their lives. For example, children of 16 and 17 can, in principle, make their own decisions. Their parents must, however, be involved in the decision-making process regarding the termination of their life. For children aged 12 to 16, the approval of the parents or guardian is required.

5. Finally, the legislation offers an explicit recognition of the validity of a written declaration of will regarding euthanasia. The presence of a written declaration of will means that the physician can regard such a declaration as being in accordance with the patient's will. The declaration has the same status as a concrete request for euthanasia. Both oral and written requests allow the physician legitimately to accede to the request. However, he or she is not obliged to do so. And he or she may only accede to the request while taking into account the due care requirements mentioned in the Act. The due care requirements must be complied with, regardless of whether it involves a request from a lucid patient or a request from a non-lucid patient with a declaration of will. In each case the doctor must be convinced that the patient is facing interminable and unendurable suffering. If he or she believes that this is not so, he or she may not accede to the request for euthanasia, no matter what the declaration of will states.

6. In all cases, the physician must report his or her act to the municipal pathologist. The report is examined by one of the five regional review committees[22] to determine whether it was performed with due care. The judgement of the review committee is then sent to the Public Prosecution Service, which uses it as a major factor in deciding whether or not to institute proceedings against the physician in question.

7. If the committee is of the opinion that the physician has practised due care, the case is closed. If not, the case is brought to the attention of the Public Prosecutor. The Public Prosecutor does of course have the power to launch his own investigation if there is a suspicion that a criminal act may have been committed.

8. According to the aforementioned survey published by The Lancet on 2 August 2003, there has been no significant rise in the number of cases of euthanasia and medically assisted suicide in recent years in the Netherlands, despite the constantly increase in the overall number of deaths.

Appendix 2

The new Belgian legislation

9. The Belgian Law on Euthanasia came into force on 23 September 2002. It built on the Dutch experience, but it has its own specific characteristics. By euthanasia is understood "an act practisced by a third party intentionally, ending the life of a person at that person's request."

10. Doctors who practise euthanasia commit no offence if they respect the prescribed conditions and procedures, and have ascertained that:

- the patient is a person of full age or an emancipated minor, possessing legal capacity and aware of what he/she is doing when he/she formulates the request (which must be made in writing);

- the request has been made voluntarily, carefully and repeatedly, and is not the result of outside pressure;

- the patient's medical state is hopeless, and he/she is experiencing constant, unbearable physical or mental suffering, which cannot be relieved and is caused by a serious and incurable injury or pathological condition.

11. Beforehand, doctors must always:

1. inform patients of their state of health and life expectancy, discuss their request for euthanasia with them, and also review with them forms of treatment which are still possible, as well as palliative care and its consequences. They must decide, with patients, that their state admits of no other reasonable solution, and that their request is wholly voluntary;

2. satisfy themselves that patients' physical or mental suffering is permanent, and that their wishes are unchanging. For this purpose, they should talk to patients several times, at intervals which are reasonable in terms of their evolving condition;

3. consult another doctor on the serious and incurable nature of the condition, indicating their reason for doing so. The doctor consulted must inspect the medical file, examine the patient and satisfy himself/herself that the latter's physical or mental suffering is constant and unbearable, and cannot be relieved, and must prepare a report on his/her findings. The doctor consulted must have no connection with the patient or the patient's doctor, and must have a specialised knowledge of the pathology in question. The patient's doctor must inform the patient of the results of this consultation;

---

[22] The regional review committees, already established in the Netherlands before the new legislation, are composed of at least three (or if more always an uneven number of) members: a legal expert as chairman, a doctor, and an expert in the field of ethics or philosophy. For each of the members, one or more substitutes are appointed. To monitor the uniformity of the assessments of the different review committees, the chairs of the committees consult regularly in a meeting attended by representatives of the Council of Procurators-General and the Health Care Inspectorate of the State Supervisory Agency for Public Health.

4. if a medical team is providing regular treatment for the patient, his/her request should be discussed with all or some of its members;

5. if the patient so desires, his/her request should be discussed with relatives whom he/she designates;

6. care must be taken to ensure that the patient has been able to discuss his/her request with persons whom he/she wished to talk to.

12. If death is not expected within a short period of time - in other words, for non-terminally ill patients, the physician must request a consultation with a third physician, either a psychiatrist or a specialist in the patient's pathology. In that case a delay of at least one month between the request and the act of euthanasia has to be observed.

13. Like the Netherlands, Belgium has established a system of control. The physician has to declare the act of euthanasia to a Federal Evaluation and Control Commission, which comprises 16 members: 8 medical doctors (including at least 4 academics), 4 lawyers, and 4 persons familiar with the problems of patients suffering from an incurable disease. This Commission has a second function: to establish, every other year, a statistical and evaluation report and to make recommendations.

14. The living will, called "advance declaration", is officially recognised but strictly limited to the state of irreversible unconsciousness of the person.

15. Although no physician is bound to perform euthanasia, a physician who, exercising his or her freedom of conscience, refuses to perform euthanasia, must transfer the patient's medical record to a colleague of the patient's choosing.

16. The law does not mention "assisted suicide". It therefore does not specify the method to be used by the physician, even though he or she must describe it in the official form to be forwarded to the Federal Evaluation and Control Commission.

17. It is worth dwelling on some of the arguments put forward by the Belgian *Conseil d'Etat*, (Supreme Administrative Court) which underline its conclusion that the bill (now law) on euthanasia was not incompatible with the provisions of the European Convention on Human Rights. The Court noted in particular, after analysis of the relevant jurisprudence of the European Court of Human Rights, that the positive obligation incumbent on Parties to protect the right to life must be balanced notably against the individual's right of self-determination.[23] This meant that the obligation of the authorities to protect the right to life (Article 2) must be balanced against the right of the individual to be protected from inhuman treatment or punishment (Article 3) and against his or her right to physical and moral integrity, deriving from the right to respect for private life (Article 8). The Convention offered no guidance as to how this conflict between fundamental rights should be resolved.

18. The *Conseil d'Etat* noted that one of the essential characteristics of the debate on euthanasia was that it raised difficult and fundamental ethical questions which necessitated making a choice between opposing ethical conceptions. As to who should make such a choice, the Court referred to a case concerning Norwegian law on abortion in which the European Commission of Human Rights agreed with the Norwegian Supreme Court in saying:

"It is not a matter or the courts to decide whether the solution to a difficult legislative problem which the legislator chose when adopting the Act on Termination of Pregnancy of 1978, is the best one. On this point, different opinions will be held among judges as among other members of our society. The reconciliation of conflicting interests which abortion laws require is the legislator's task and the legislator's responsibility. (...) Clearly, the courts must respect the solution chosen by the legislator"[24]

---

[23] In this connection, account must be taken of the strength of the will of the person concerned. For example, when an individual is incapable of deciding for himself or herself, the obligation of the authorities is greater than when he or she is capable of making decisions about his or her own life.

[24] European Commission of Human Rights, Decision of 19 May 1992, H.v./Norway, 17.004/90, D.R. vol. 73, (155), p. 168, §1.

19. As to the question whether the Norwegian law was compatible with Article 2 ECHR, the Commission concluded that:

« ...assuming that the Convention may be considered to have some bearing in this field, the Commission finds that in such a delicate area the Contracting States must have a certain discretion »....[25]

20. Similarly, it was up to the legislator, exercising his or her discretionary power, to resolve the conflict between opposing ethical conceptions at issue in the debate as to whether or not to decriminalise euthanasia. Judges must respect this power of appreciation of the legislator and could not take his or her place. However, this discretionary power was not unlimited. The obligation to protect the right to life had to be assessed in the light of the conditions and procedures accompanying the law on euthanasia. On this point, the *Conseil d'Etat* was satisfied that the bill (now law) remained within the limits set to the margin of appreciation allowed the national authorities under Article 2 of the Convention.

21. The Federal Evaluation and Control Commission recently published its First Report to the Legislative Chambers, covering the period 22 September – 31 December 2003[26]. The report indicates that the number of declared deaths by euthanasia accounts for 0.2% of all deaths, and 0.25 % if we take the statistics from the last nine months, with a higher percentage in the Flemish area of the country. The Commission noted no abuses of the system, and considers that no further legislation is required.

Information document on the conclusions of the Federal Commission for Euthanasia Control and Evaluation (Belgium) (22 September 2002 – 31 December 2003)

1. The number of declared cases of euthanasia appears to have levelled out, after the initial months of application of the law, at about twenty declarations per month, most of which are written in Dutch.

2. Euthanasia is carried out at the patient's home in almost half of cases, seldom in rest homes and clinics.

3. The complaints leading to euthanasia are, as stipulated by law, incurable and severe without any possible medical solution. A very substantial majority of cases involve generalised or seriously disabling cancers expected to cause imminent death and, to a lesser extent, progressive neuromuscular diseases of a fatal nature. Other pathologies are seldom at issue. The intolerable and unrelievable suffering complained of by patients is often multiple and usually both physical and mental.

4. Acts of euthanasia carried out for complaints not expected to cause imminent death are comparatively rare and chiefly concern progressive neuromuscular diseases of a fatal nature, involving tetraplegia or severe multiple paralysis.

5. So far there has only been one instance of euthanasia performed on an unconscious patient on the basis of an anticipated declaration (it should be recalled that the Royal Decree on anticipated declarations was not published until 2 April 2003 and that as things stand the registration of the declaration prescribed by law has still not been brought into operation).

6. Euthanasia was in most cases performed on middle-aged patients; it is uncommon under the age of 40 and over the age of 80 years.

7. In the overwhelming majority of cases, the act of euthanasia is carried out correctly and in accordance with the data available from medical literature, firstly by inducing deep unconsciousness; whenever there is a running commentary on the technique used, it mentions that death occurs peacefully within a few minutes.

---

[25] Ibid.
[26] See www.health.fgov.be/AGP/fr/euthanasia/F5764RapportEuthanasieFR.pdf.

8. No declaration has revealed infringement of the essential conditions prescribed by the law. Following the initial months of application of the law. during which errors of interpretation relating mainly to points of procedure were noted, the quality of the declarations has steadily improved. The finalisation of a new registration document will probably rectify any errors of interpretation that might still persist.

9. Besides the consultations required by law, numerous doctors and palliative care teams have been voluntarily consulted.

10. The commission does not propose any fresh legislative initiatives, believing that in the context of its assignment it has collected no evidence that would warrant such initiatives. However, it perceives the need for informational work directed both at the medical profession and at the public. Information to doctors should in particular be designed to give them the necessary grounding for effective action as consultants on end-of-life issues.

11. The commission suggests that investigations of all medical decisions at the end of life be regularly organised in our country, as they have been since 1990 in the Netherlands.

Appendix 3

Swiss law

22. Swiss law is a special case in Europe. There are no specific laws on euthanasia, but the Criminal Code contains provisions which may be applied to it. Article 114 lays down that a person who kills another at the latter's serious and insistent request and for an honourable reason, eg on compassionate grounds, shall be liable to a prison sentence of between three days and three years. Article 115 makes incitement to and assistance with suicide a punishable offence, but solely where there is a selfish motive. These provisions have been seldom implemented since their introduction in 1942.

23. In fact, Article 115 was not based on any medical or end-of-life considerations: originally, in the 19th century, it aimed at exonerating from punishment anyone, for example, who lent a weapon to a friend wishing to commit suicide because of an unhappy love affair or an affront to his honour. Nowadays, assistance to suicide as provided by such associations as Exit or Dignitas is not punishable, precisely, thanks to this provision, even though this was not at all the legislator's intention. Thus, assistance to suicide, in the absence of any selfish motive, goes unpunished, whilst doctors who carry out euthanasia, even where it is demanded by the patient, are in fact sanctioned. Many political initiatives have been submitted in recent years aimed at either tightening up the regulations on assistance to suicide or recognising certain forms of euthanasia. Discussions so far have shown the difficulty of achieving a majority in favour of either stricter or more liberal legislation. Parliament finally adopted a motion mandating the Government to submit proposals for legislation on indirect and passive euthanasia and to take measures to promote palliative medicine. Discussions were intense in scientific and professional circles. As pointed out above (paragraph 16), the Swiss Academy of Medical Sciences has formulated new guidelines on provision for patients at the end of life. We feel that we must quote the Academy's position on assistance to suicide: "in this kind of situation between life and death, physicians may be faced with a difficult conflict. First of all, assistance to suicide does not form part of medical activity, because physicians have the duty to use their medical skills to treat, relieve and support their patients. Secondly, they must take account of their patients' wishes, which might mean respecting a moral and personal decision taken by a physician to provide a dying patient with assistance in committing suicide in certain special cases. This places the onus on all physicians to verify whether the following minimum requirements are fulfilled:

- the patient's disease is such as to indicate that his/her life is drawing to an end;

- alternative treatments have been offered and, if so desired by the patient, implemented;

- the patient is capable of discernment. His/her desire to die has been carefully thought through, does not stem from any external pressure, and is persistent. This state of affairs must be verified by a third person, who must not necessarily be a physician".

- Collegiate decisions to halt treatment for unconscious patients

The new element where *unconscious patients* are concerned is the provision in the fourth sub-paragraph of Article L 1111-4 that treatment may not be limited or halted until a collegiate procedure laid down in regulations has been followed, or without having consulted the trusted person, the family or a close relative.

- Giving concrete form to health establishments' palliative care obligations

As it currently stands, Article L 1110-9 of the Public Health Code recognises every patient's right to access to palliative care. In order to give this right a more concrete form, it is suggested that an obligation to create designated palliative care beds should be introduced into the law and that palliative care staff be required in every major department playing a significant role in this kind of care. This obligation would be included in the provisions relating to the contracts covering several years concluded by regional hospitals agencies (ARH) with public and private health establishments (Article L 6114-2 of the Public Health Code), and in those relating to health establishments' own five-year plans (Article L 6143 *et seq*).

- Recognition of specific rights for patients in the end-of-life phase

Such recognition presupposes that these rights are identified in the Public Health Code. This is why, in addition to a section entitled "General Principles", encompassing Articles L 1111-1 to 1111-9 of the Public Health Code, a second section, entitled "Expression of patients' wishes during the end-of-life phase" would comprise all the articles relating to such patients, starting with a newly created Article L 1111-10.

Recognition of these rights needs to give rise to provisions in three areas: refusal of treatment by conscious patients, affirmation of the role of the trusted person and the taking into account of the instructions given by patients in advance.

With reference to a person in an advanced, or the terminal, phase of an incurable serious disease, whatever its cause, the end-of-life criterion would draw on that adopted by the ANAES (national health accreditation and evaluation agency). A new Article L 1111-10 would be drafted to regulate this situation. It would empower doctors to limit or halt any treatment if so decided by a patient in an advanced, or the terminal, phase of an incurable serious disease, whatever its cause. In such a case, doctors should respect patients' wishes, after having informed them of the consequences of their decision, but would be required to provide palliative care.

The trusted person in this context would have his or her role increased. In pursuance of the current Article L 1111-4, when the patient is no longer in a condition to express his or her wishes, no action may be taken or investigation carried out, other than in an emergency or where consultation is impossible, without the trusted person or, failing him or her, a close relative having been consulted. The introduction of this system would not be without its problems. It therefore seems desirable to move further along the lines followed since 2002, the year of adoption of the law on patients' rights and the quality of the health system, by reinforcing the status of the trusted person. To this end, that person's opinion should prevail over any other non-medical opinion.

Where instructions given in advance are concerned, these might comprise one element of the manifestation of the wishes of a patient now unconscious. They would accordingly be regarded as having indicative value, subject to their having been recorded less than three years before the patient lost consciousness. A new Article L 1111-12 would contain these provisions.

Lastly, harmonisation of the wording of the Public Health Code with that of the medical code of professional ethics seems desirable. With this in mind, it would be appropriate for the Public Health Code to refer to the collegiate procedure which should be included in Article 38 of the medical code of professional ethics for cases in which the patient is no longer in a condition to express his or her wishes and where the doctor decides to limit or halt futile treatment incapable of improving the patient's condition. This would be the purpose of a new Article L 1111-13 of the Public Health Code.

*
* *

These proposals as a whole should undeniably constitute progress for both patients and health professionals. For the latter, thanks to these provisions, Article 122-4 of the Penal Code, which exonerates from criminal responsibility anyone performing an act prescribed or authorised by the law, would find its full justification; indeed, a doctor complying with his or her obligations of transparency and collegiality would not be criminally responsible, unlike one who failed to fulfil them.

These new rights for patients and new obligations for doctors should again be viewed in the more general context - already referred to - of our society's relations with death. The development of palliative care since the eighties has, discreetly but surely, brought about changes. The recognition of new patients' rights, thanks to the provisions on the limitation or cessation of treatment, to instructions given in advance and to trusted persons, will also enable every person both to deal with the end of his or her life and to prepare for death better. The collegiate nature and transparency of the medical decision help to meet this same concern, with these procedures both supporting the medical profession in its good practice and helping to establish trusting dialogue with dying persons and their families.

Without making any claim to encompass the wide range of situations which could occur, this bill is thus intended to instil in society a greater serenity at the approach of death.

Reporting committee: Social, Health and Family Affairs Committee

Reference to committee: Doc. 9898, Ref. No. 2960 of 30 April 2004

Draft resolution adopted on 17 December 2004 by 11 against 7 and one abstention

Members of the committee: **Mr Marcel Glesener** (Chair), **Mrs Christine McCafferty** (1st Vice-Chair), Mr Ioannis Dragassakis (2nd Vice-Chair), **Mrs Patrizia Paoletti Tangheroni** (3rd Vice-Chair), Mrs Birgitta Ahlqvist, Mr Giuseppe Arzilli, **Mrs Maria Eduarda Azevedo**, Mrs Helena Bargholtz, MM. Miroslav Benes, Andris Berzinš, Jaime Blanco, Bozidar Bojovic, Mrs Marida Bolognesi (Alternate: **Mr Rino Piscitello**), MM. Dumitru Braghis, **Christian Brunhart**, Gheorghe Buzatu, **Yüksel Çavusoglu**, Igor Chernyshenko, Doros Christodoulides, Mrs Minodora Cliveti, MM. Luis Eduardo Cortès, **Thomas Cox**, Imre Czinege, Jordi Daban Alsina, Mrs Helen D'Amato, MM. **Dirk Dees**, **Karl Donabauer**, Claude Evin, **Paul Flynn**, Jean-Marie Geveaux, Igor Glukhovskiy (Alternate: **Mr Victor Kolesnikov**), Tony Gregory, Ali Riza Gülçiçek, Irfan Gündüz, Alfred Gusenbauer, Mykhailo Hladiy, Bent Høie, Mrs Sinikka Hurskainen, MM. Denis Jacquat, Zbigniew Jacyna-Onyszkiewicz, Ramon Jaúregui (Alternate: **Mrs Bianca Fernandez-Capel**), Andras Kelemen (Alternate: **Mr Attila Gruber**), Orest Klympush, Baroness Knight of Collingtree (Alternate: **Mr Michael Hancock**), MM. Shavarsh Kocharyan, Mrs Katerina Konečná, MM. Slaven Letica, Gadzhy Makhachev, Tomasz Markowski, Christian Menard, Mrs Liljana Milićević, MM. Nikolay Mladenov, Philippe Monfils, Mrs Nino Nakashidzé, Mrs Vera Oskina, MM. Janez Padobnik, Marek Pol, Virgil Popa, Francis Poty, Troels Lund Poulsen, Fiorello Provera (Alternate: **Mr Francesco Tirelli**), Anatoliy Pysarenko, Mrs Valentina Radulović-Šćepanović, MM. Helmut Rauber, Walter Riester, Enrico Rizzi (Alternate: **Mr Andrea Rigoni**), Mrs Maria de Belém Roseira, Mrs Katrin Saks, MM. Walter Schmied, Samad Seyidov, Mrs Naira Shakhtakhtinskaya, Mr Ossur Skarphédinsson, Mrs Darinka Stantcheva, Mrs Rita Streb-Hesse, **MM. Algirdas Sysas**, Konstantinos Tassoulas, **Mrs Jozephina Topalli**, Mr Milan Urbáni (Alternate: **Mr Vojtech Tkáč**), Mrs Ruth-Gaby Vermot-Mangold, (Alternate : **Mr Dick Marty**), Mr Bart Van Winsen (Alternate: **Mrs Marie-Louise Bemelmans-Videc**), Mrs Verena Wohlleben, **Mr Andrej Zernovski**, ZZ..

NB: The names of those members present at the meeting are printed in bold

Head of Secretariat: Mr Géza Mezei

Secretaries: Mrs Agnès Nollinger, Mrs Christine Meunier, Mrs Dana Karanjac