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Belgium: Mandatory Referral for Euthanasia

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Introduction

Belgium legalized euthanasia (not assisted suicide) in September, 2002 for persons, not necessarily terminally ill, who are in “constant and unbearable physical or mental suffering that cannot be alleviated.”¹

The *Euthanasia Act* (S. 14) provides that physicians cannot be compelled to perform euthanasia and other persons cannot be forced to assist in it. It also requires that a physician who declines to perform euthanasia must transfer the patient’s medical file to a physician or person designated by the patient if requested to do so, but there is no requirement to refer or otherwise actively facilitate the procedure.

A knowledgeable professional later told a British House of Lords committee that fewer than 50% of Belgian physicians and less than 80% of the public were in favour of euthanasia when the euthanasia bill was introduced.² Both he and another Belgian commentator attributed its introduction and swift passage not to needs expressed by patients and the medical community, but primarily to politics: a change of government and later political exigencies.³

Given these circumstances, it is not surprising that the release of a joint *Policy Statement on End of Life Decisions and Euthanasia* in December, 2003 was accompanied by reports that many general practitioners were unfamiliar or uncomfortable with the relatively new euthanasia law, and that a “change of attitude” was required “from many doctors.”⁴ The signatories to the joint statement were the Belgian Association of General Practitioners, the Academy at the Catholic University of Leuven and the Academy for Knowledge at the University of Ghent. The document made a number of claims that raised important questions about freedom of conscience among health care workers:

1. euthanasia is part of palliative care;
2. physicians must ensure that patients are given information that allows them to opt for euthanasia;
3. physicians who object to euthanasia are obliged to refer patients for the procedure.

Thus, the Project initiated correspondence about the joint statement with the designated contact at the Belgian Association of General Practitioners.⁵ Unfortunately, after an initial response,⁶ the Association did not respond to the Project’s further efforts to continue the discussion.⁷ The correspondence is offered in English and Dutch to encourage international dialogue on an important subject.

Frequency of euthanasia in Belgium

During the first year of legalization about 200 cases were reported.⁸ Fifteen months after the law was passed there had been an average of about 20 cases per month, and 30 cases per month by April, 2005.⁹

60% of the euthanasia occurred in hospitals,¹⁰ which employ about half the people working in the health care sector.¹¹ While this suggests that the procedure may be encountered by a large number of health care workers, the only medical professionals legally authorized to perform euthanasia are physicians.

Belgian doctors (2002)	With practice	Total
General practitioners & generalists in training	14,541	18,367
Specialists & specialists in training	25,758	27,901
Total	40,299	46,268

TABLE A - Source : Ministry of Social Affairs, Public Health and Environment¹²

Based the figures from Table A and a monthly rate of 30 reported euthanasia cases (360 annually), each requiring the participation of at least two doctors, a Belgian doctor with a practice has less than a 1% chance of participating in euthanasia over the course of a year, rising over five years to over 4%.

It is appropriate to consider the situation of pharmacists, since they dispense the drugs required for euthanasia.¹³ Based on the current euthanasia rate, each of Belgium's 11,775 pharmacists has a 3% chance of being asked to supply drugs for lethal injection during one year of practice: 30% over ten years. It is interesting to note that, though physicians are the usual focus of attention in the health care sector when euthanasia is discussed, there is a higher probability that a pharmacist will be asked to facilitate the procedure.

These estimates do not take into account factors that might increase or decrease the probability in different locations or in different kinds of medical practice or specialties, nor the possibility that the actual number of euthanasia cases may be two to five times higher than the number reported.¹⁴

“Change of attitude:” Euthanasia as palliative care

The joint statement opens with the assertion that a GP's responsibilities include “aid in dying and everything connected thereto.” Bearing in mind the loss of precision that can accompany translation, one should not to read too much into this. Though “aid in dying” is one of the phrases favoured by euthanasia advocates, it need not be understood as implying either euthanasia or assisted suicide. On the other hand, such ambiguous terminology is likely to cause confusion and even controversy.

The second policy position in the joint statement is unambiguously controversial:

Euthanasia is one of the possible choices of dying and should be enclosed in the total palliative care encompassing care of the individual.

And later:

Euthanasia is a possible choice at the end of life included in a total package of palliative care.

This is the goal of euthanasia advocates like Michael Irwin, a British physician who has been struck from the role of practitioners for attempting to help a terminally ill friend commit suicide. “I think,” he told a BBC interviewer, “that physician assisted suicide should be an option within good palliative care services.”¹⁵

In correspondence with the Association, the Project pointed out that palliative care is widely understood as “the relief of the burden of pain and suffering caused by disease so that patients live comfortably until they die” - not causing the death of a patient - and that the proposed redefinition of ‘palliative care’ would have significant consequences for anyone working in the field. The Association replied that it does not accept such a “dichotomous vision (palliative care vs. euthanasia),” but prefers a “broader” definition that takes fuller account of “the patient’s perception.” By way of explanation, it quoted from a statement issued by the Flemish Palliative Care Federation in September, 2003 (*Federatie Palliatieve Zorg Vlaanderen - FPZV*):

Palliative care and euthanasia are neither alternatives nor opposites. When a doctor is prepared to accede to the euthanasia request of a patient who continues to find life unbearable despite the best treatment, then there is no gap between the palliative care given previously by the doctor and the euthanasia he applies now; on the contrary. In such a case, euthanasia forms part of the palliative care with which the doctor and the care team surround the patient and his or her nearest. . .

. . . in the context of a euthanasia request, carers and patients can expect the palliative teams to do more than merely inform them about potential palliative alternatives and palliative support where necessary. Carers and patients can also address themselves to the networks and teams for information and support directly related to euthanasia and the Euthanasia Act. Team doctors can take on the role of the ‘other’ or ‘second’ doctor in the euthanasia procedure.

It appears that this statement¹⁶ reflects a significant shift from the earlier position of the Federation, which had originally argued that palliative consultation should *precede* steps taken toward euthanasia, be confined to the discussion of “possible palliative alternatives,” and not include a review of a euthanasia request. One reason given for maintaining this division of responsibilities was to ensure that the public would not confuse euthanasia with palliative care.¹⁷ Given its acceptance of euthanasia as an aspect of palliative care, it seems the distinction ceased to be important.

The shift is also reflected in a broadened view of multidisciplinary collaboration. The FPZV first emphasized this because it recognized that no single physician could provide palliative care alone, and that few had sufficient expertise in palliative medicine to adequately advise or meet the needs of the patient.¹⁸ This concern remains evident in the joint statement from the Association and universities, but to it is added a desire, twice repeated, to “avoid polarization” within the medical

profession, presumably between those who support euthanasia and those who do not. Thus, palliative care team members are said to be available for consultation about euthanasia. It is also noteworthy that the Association and universities are collaborating with LevensEinde Informatie Forum (LEIF: Life'sEnd Information Forum¹⁹), which was described by Prof. van den Eynden as a group of about 200 doctors who are promoting their availability for euthanasia.²⁰ In sum, the multidisciplinary approach that was originally associated to the need for assistance in palliative care now includes physicians with expertise in euthanasia.

The dissolution of conceptual boundaries between euthanasia and palliative care is further illustrated by the FPZV's suggestion that a member of a palliative care team might act as the second physician in processing a euthanasia request under Belgian law.²¹ Paradoxically, the FPZV insists that palliative care doctors should not actually carry out euthanasia. But if euthanasia "forms part of . . . palliative care," so that a palliative care physician might support a euthanasia request, it is not at all clear why palliative care physicians should not directly participate in the procedure. Indeed, the rationale offered for this division of responsibilities seems incoherent.²² Such a division can only be justified by maintaining the kind of distinction between palliative care and euthanasia denied by the FPZV statement.

Consistent with the view that euthanasia is part of a "total package palliative care," the joint statement opposes the establishment of euthanasia teams or facilities and argues against the concept of euthanasia as a form of treatment distinct from other kinds of medical interventions. Instead, it recommends that the second physician involved in the euthanasia process "have specialized knowledge about palliative care and end of life decisions," which is consistent with the later view of the FPZV that the second doctor might be a member of a palliative care team.

Euthanasia vs. palliative care

The incorporation of euthanasia into a continuum of care that no longer distinguishes between palliation and deliberately causing death is inconsistent with internationally accepted concepts. Almost 90% of 2,200 palliative caregivers polled in Europe in 1999 rejected euthanasia.²³ Neither euthanasia nor assisted suicide is included in the World Health Organization's definition of palliative care, which explicitly excludes hastening death:

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care . . . intends neither to hasten nor postpone death."²⁴

Similarly, there is no reference to euthanasia in the definition offered in the *Oxford Textbook of Palliative Medicine*, which describes palliative care as "the study and management of patients with active, progressive, far-advanced disease for whom the prognosis is limited and the focus of care is on the quality of life."²⁵ The American Academy of Hospice and Palliative Medicine addressed the issues of euthanasia and assisted suicide in a formal statement that avoided judgement on the morality of the procedures but affirmed that "the appropriate response to the request for physician-assisted suicide is to increase care with the intent to relieve suffering, not to deliberately cause death."²⁶ And, rejecting the concept of "euthanasia as the final stage of good palliative

care,” Canadian Professor Margaret Somerville, founding director of the McGill Centre for Medicine, Ethics and Law at McGill University, wrote that the idea “is an example of putting a ‘medical cloak’ on euthanasia,” implicitly separating the procedure from the practice of medicine altogether.²⁷

Somerville’s comment clearly reflects an anti-euthanasia position, but it is a view shared by innumerable health care workers and arguably reflects a vision of palliative care that is closer to that articulated by the World Health Organization, “dichotomous” though it may be with respect to euthanasia.

Legalization of euthanasia or assisted suicide cannot help but affect health care workers who share Somerville’s views, especially if the procedures are incorporated into “normal health care” rather than introduced as a specialty and/or provided through specialized facilities. However, the potential for conflict will be considerably greater if legalization leads to the redefinition of palliative care advocated by the Belgian universities and professional associations.

Communication and informed consent

The joint statement offers some sound suggestions about physician-patient communications:

- objecting physicians should give timely notice of their views to patients;
- professional associations should assist in developing strategies that will allow objecting physicians to deal with requests for euthanasia in a manner that is respectful of the patient and consistent with their own principles;
- end-of-life discussions should be recorded in the patient’s medical file;
- an “information and communication contract” might be used to document the physician-patient understanding of end-of-life issues.

Applying the principle of “informed consent” or “informed choice,” the Association would have physicians discuss “all possibilities” with a patient “so that he is well informed and can opt for euthanasia.” In this context one also encounters the euthanasia-palliative care connection:

In some cases the physician must initiate these discussions to ensure that less well-informed patients are not denied their right to choose euthanasia. In the palliative care phase these discussions should be recorded in the palliative care file.

The expectation is not simply that physicians respond to patient requests for information about euthanasia, but that euthanasia be proposed as an option to every patient in what might be called “approaching end-of-life circumstances,” whether or not the patient has expressed interest in it.

This is rather like requiring physicians to propose abortion to every woman found to be pregnant, as if every pregnant woman ought to contemplate having an abortion and would be pleased to be reminded by her physician that it is an option.

Granted that a patient must know that euthanasia is available in order to be able to make a choice for *or against* it, the wording of the policy - “so that he . . . can opt for euthanasia” and “to ensure that . . . patients are not denied their right to choose euthanasia” - seems to reflect a lack of balance. It suggests a greater interest in marketing a newly available procedure than in simply presenting

information so that a patient can make a choice.

On the other hand, the wording might reflect a concern that patients may be unaware that euthanasia is available, even though the legalization of the procedure was widely publicized and accompanied by controversy. In that case, as time passes and knowledge of the legality and availability of the procedure becomes more widespread, one would find less justification for a presumption of ignorance.

It is often argued that no moral culpability can be attached to the mere provision of information to a patient. That this is not necessarily true is demonstrated by the suspension of a British doctor solely because he provided information to two ‘undercover’ journalists about how to obtain a kidney transplant from a live donor through the organ trade abroad. Britain’s General Medical Council ruled that he had not participated in the trade, but that he had encouraged it by answering questions about it.²⁸ It appears to have been the view of the General Medical Council that a physician should not volunteer information or offer advice that would suggest to a patient that the purchase of organs from a live donor is morally or ethically acceptable.

The communication problem faced by health care workers who object to euthanasia for reasons of conscience is to avoid acting or speaking in a way that is false to their convictions about the moral nature of the act, while providing the information required by law or by prevailing ethical opinion. The patient may choose euthanasia, but a conscientious objector generally does not wish to positively contribute to that choice, for to do so would compromise his personal integrity. At the same time, an objector ought to be aware that he may positively contribute to a choice for euthanasia by alienating the patient.

Nonetheless, physician-patient communication about euthanasia in Belgium may be less complicated than analogous communication about abortion in North America. While the Belgian *Law Regarding the Rights of the Patient* compels physicians to inform patients about euthanasia,²⁹ the Association explained that an objecting doctor is free to inform the patient of his moral position and to express an opinion about the moral acceptability of the patient’s choice. “Thus,” wrote the Association, “moral neutrality does not exist in respect of a euthanasia request.”

In contrast, North American physicians who object to abortion are sometimes accused of acting unethically and being “judgmental” simply because they explain their objections to a patient. One is sometimes left with the impression that the accusers want objectors to falsify their views by presenting abortion as a morally neutral choice.³⁰ This would nullify the objector’s moral outlook in favour of their own, under the guise of ‘neutrality’. Professor J. Budziszewski, an advisor to the Protection of Conscience Project, describes such ‘neutrality’ as “bad-faith authoritarianism... a dishonest way of advancing a moral view by pretending to have no moral view.”³¹ It is gratifying, in this respect, to see what seems to be a more open and honest approach in Belgium.

Mandatory referral for euthanasia

As noted previously, if a patient seeking euthanasia asks an objecting physician to send his medical file to another doctor, the Belgian *Euthanasia Act* requires the objector to do so. However, contrary to assertions made by Prof. van den Endyn,³² the law does not require more active facilitation of the procedure. The Flemish Palliative Care Federation is silent on the issue of referral, but the joint

statement asserts that an objecting physician must not only give patients timely notice of his position, but must “refer the patient to another physician with a different view.” At another point the joint statement insists that an objecting physician “work together” with the patient to find a willing colleague. The experience of the Project is that most conscientious objectors to euthanasia would refuse to do this because they would see it as active and morally culpable collaboration in the act.

When questioned about the policy of mandatory referral, the Association replied that it would be sufficient if a physician were to advise the patient of the availability of an official telephone “help-line” that provides information about accessing euthanasia services and other end-of-life information, so that the patient would not be “left in the lurch.” While this seems a far less stringent requirement, the joint statement remains unchanged, and, by ceasing correspondence, the Association declined to explain which was the official position of the joint signatories: mandatory referral, as set out in the joint statement, or the “help-line” option proposed in its letter.

Autonomy, informed consent and shared decision making

“[A]cceptance of the autonomy of the patient” is the underlying principle that must inform discussion of euthanasia, according to the joint statement, which also stresses, in English, “informed consent” and “shared decision making” [“Communicatie en overleg vormen de kern van het ‘informed consent’, de ‘shared decision making’ . . .”]. This suggests that the document has been strongly influenced by North American or English sources, as yet unidentified by the Association or universities.

“Autonomy,” “informed consent” and “shared decision making” have, unfortunately, become terms of art for opponents of freedom of conscience in health care, particularly with respect to contraception and abortion. For example, a medical student who was unwilling to perform abortions, prescribe oral contraceptives or refer patients for these services was given a failing grade by a preceptor who stated that he had denied “[t]he patient's right to autonomy and participation in the decision-making process.”³³

Social critic and constitutional lawyer Iain Benson has criticized this one-sided view of autonomy:

There is no good reason . . . to advocate that a patient's autonomy should trump the autonomy of the professional health-care worker just because the two views conflict. What is needed . . . is an examination of how to accommodate conscience and religious views within the contemporary technocratic and often implicitly anti-religious paradigm of certain aspects of modern medicine. . . . An analytical framework of some sophistication is necessary to ensure maximal respect for and accommodation of differing views in society. . .

The real issue, where there is a conflict of views between people regarding involvement with a procedure or drug, is not settled by reference to one person's "autonomy" but by reference to another principle, that of "justice" (defined as "rendering a person their due..."). For it is there, in the order of justice, that competing claims must be reconciled . . .³⁴

The concept of “shared decision making” - oversimplified within the context of the joint statement -

is inapplicable in cases of conscientious objection. There can be joint deliberation, but if, in the end, there is a fundamental disagreement about what the patient wants and the physician is willing to provide, all that remains is an agreement to disagree and a parting of ways.³⁵

A lesson for other countries

Belgium is a small country, one of only four jurisdictions worldwide where euthanasia or assisted suicide is legal. Nonetheless, no one concerned with freedom of conscience for health care workers can afford to take lightly the fact that a professional medical organization and two universities, one of them Catholic, now advocate the incorporation of euthanasia into palliative care and demand that objecting physicians facilitate euthanasia by referral. Unchallenged, this precedent will be cited to undermine freedom of conscience in other countries, where the kind of arguments and claims found in the joint statement are already being used for that purpose.

Notes:

1. *The Belgian Act on Euthanasia of 28 May, 2002*, Section 3§1. Unofficial translation by Dale Kidd under the supervision of Prof. Herman Nys, Centre for Biomedical Ethics and Law, Catholic University of Leuven, Belgium. *Ethical Perspectives* 9 (2002) 2-3, p. 182. [<http://www.kuleuven.ac.be/cbmer/viewpic.php?LAN=E&TABLE=DOCS&ID=23>] (Accessed 2005-10-27).
2. House of Lords Select Committee on Assisted Dying for the Terminally Ill Bill. *Minutes of Evidence; Examination of Witnesses*. 13 January, 2005 (Questions 1880 - 1899): Professor Bart van den Eynden (Q1881) [<http://www.publications.parliament.uk/pa/ld200405/ldselect/ldasdy/86/5011314.htm>] (Accessed 2005-10-25) Professor van den Eynden is a Professor in Palliative Care at Antwerp University and a palliative care physician responsible for a 12 bed palliative care unit and of the palliative support team covering 1,000 acute hospital beds in Antwerp. He is an alternate on Belgium's 16 member Federal Inspection and Evaluation Committee on Euthanasia.
3. “. . . the whole movement for legislation of euthanasia in Belgium did not arise from a real caring for the suffering patient but started as a political concern and turned into an ideological debate with two opposite camps.” House of Lords Select Committee on Assisted Dying for the Terminally Ill Bill. *Minutes of Evidence; Examination of Witnesses*. 13 January, 2005 (Questions 1855 - 1859): Professor Bart van den Eynden(Q1855) [<http://www.publications.parliament.uk/pa/ld200405/ldselect/ldasdy/86/5011314.htm>] (Accessed 2005-10-25)
See also Broeckaert, B. Janssens, R. “Palliative Care and Euthanasia: Belgian and Dutch Perspectives.” p.20-21 *Ethical Perspectives* 9/2-3 (June - September - 2002) 156 - 176 [<http://www.kuleuven.ac.be/ep/page.php>] (Accessed 2005-10-27)
4. “GPs 'must change attitude' over euthanasia.” *Expatica*, 5 December, 2003. [http://www.expatica.com/source/site_article.asp?channel_id=1&story_id=2889] (Accessed 2005-10-13).

5. Letter from the Administrator, Protection of Conscience Project, to the Belgian Association of General Practitioners, 23 July, 2004 [<http://www.consciencelaws.org/Examining-Conscience-Background/Euthanasia/BackEuthanasia10.html>].
6. Letter from the Belgian Association of General Practitioners to the Administrator, Protection of Conscience Project, 24 August, 2004 [<http://www.consciencelaws.org/Examining-Conscience-Background/Euthanasia/BackEuthanasia11.html>].
7. Letter from the Administrator, Protection of Conscience Project to the Belgian Association of General Practitioners, 6 October, 2004. [<http://www.consciencelaws.org/Examining-Conscience-Background/Euthanasia/BackEuthanasia12.html>] Letter from the Administrator, Protection of Conscience Project to the Belgian Association of General Practitioners, 25 April, 2005. Sent again by e-mail on 29 September, 2005 [<http://www.consciencelaws.org/Examining-Conscience-Background/Euthanasia/BackEuthanasia13.html>].
8. "Euthanasia for 200 in first year." *Expatica*, 25 November, 2003. [http://www.expatica.com/source/site_article.asp?channel_id=1&story_id=2571] (Accessed 2005-10-13).
9. "One Belgian dies each day from euthanasia procedures." *Expatica*, 21 April, 2005. [http://www.expatica.com/source/site_article.asp?channel_id=1&story_id=19352] (Accessed 2005-10-13).
10. "One Belgian dies each day from euthanasia procedures." *Expatica*, 21 April, 2005. [http://www.expatica.com/source/site_article.asp?channel_id=1&story_id=19352] (Accessed 2005-10-13).
11. Maintenance and Improvement of quality health care: The Belgian Health Care System Revisited Dr. M. MOENS Secretary-general VBS-GBSBrussels, September 27, 2003 [<http://gbs-vbs.org/dgs/g2003/gsfolio16/bhcs.htm>] (Accessed 2005-10-13).
12. In Table 5, Maintenance and Improvement of quality health care: The Belgian Health Care System Revisited Dr. M. MOENS Secretary-general VBS-GBSBrussels, September 27, 2003 [<http://gbs-vbs.org/dgs/g2003/gsfolio16/bhcs.htm>] (Accessed 2005-10-13).
13. "Belgian euthanasia cases 'exceed official reports.'" *Expatica*, 6 September, 2005. [http://www.expatica.com/source/site_article.asp?channel_id=1&story_id=23437] (Accessed 2005-10-13).
14. "There are assumptions that it is the same quantity as it is in The Netherlands. It means that at least 50 per cent is not reported and maybe it is more, but because it is not reported you do not know." House of Lords Select Committee on Assisted Dying for the Terminally Ill Bill. *Minutes of Evidence; Examination of Witnesses*. 13 January, 2005 (Questions 1860 - 1879); Professor Bart van den Eynden(Q1866) [<http://www.publications.parliament.uk/pa/ld200405/ldselect/ldasdy/86/5011313.htm>] (Accessed

2005-10-25).

Federal Control and Evaluation Commission chief Wim Distelmans suggested that, based upon Dutch experience, the actual number of Belgian euthanasia cases each month is 150, five times the reported number. Quoted in “Belgian euthanasia cases 'exceed official reports.’” *Expatica*, 6 September, 2005.

[http://www.expatica.com/source/site_article.asp?channel_id=1&story_id=23437] (Accessed 2005-10-13).

15. “For some people, you get to a certain stage when you really can say, ‘I’ve had enough of this palliative care. I’d like to kind of, kind of leave this word a bit more more quickly.’ And I think, therefore, that physician assisted suicide should be an option within good palliative care services.” Interview of Michael Irwin, 19 October, 2005. Outlook: BBC World Service [http://www.bbc.co.uk/worldservice/meta/tx/nb/outlook_wed_au_nb.ram] (Accessed 2005-10-20).

16. Federatie Palliatieve Zorg Vlaanderen, *Omgaan met euthanasie en andere vormen van medisch begeleid sterven* (september, 2003) [Flemish Palliative Care Federation, *Dealing with Euthanasia and Other Forms of Medically Assisted Death* (September, 2003) Originally at [<http://fedpalzorg.be/wemmel/teksten/Euthanasie%20-%20standpunt%20Federatie.doc>] Cached at

[http://66.102.7.104/search?q=cache:N7Nk_7UtayMJ:fedpalzorg.be/wemmel/teksten/Euthanasie%2520-%2520standpunt%2520Federatie.doc+%22Omgaan+met+euthanasie+en+andere+vormen+van+medisch+begeleid+sterven%22&hl=en] (Accessed 2005-10-27). In Dutch and English at [<http://www.consciencelaws.org/Drafts/BackEuthanasia14.html>].

17. Broeckaert, B. Janssens, R. “Palliative Care and Euthanasia: Belgian and Dutch Perspectives.” p.20-21 *Ethical Perspectives* 9/2-3 (June - September - 2002) 156 - 176 [http://www.kuleuven.ac.be/ep/page.php?LAN=E&FILE=ep_detail&ID=33&TID=57] (Accessed 2005-10-27).

18. Broeckaert, B. Janssens, R. “Palliative Care and Euthanasia: Belgian and Dutch Perspectives.” p.20-21 *Ethical Perspectives* 9/2-3 (June - September - 2002) 156 - 176 [http://www.kuleuven.ac.be/ep/page.php?LAN=E&FILE=ep_detail&ID=33&TID=57] (Accessed 2005-10-27).

19. [<http://www.leif.be/>] “Het LEIFproject is een open initiatief en bestaat uit mensen en verenigingen die streven naar een menswaardig levenseinde voor iedereen, waarbij respect voor de wil van de patiënt voorop staat.” (*The Life’s End Information Forum project is an initiative of people and associations that strives to achieve a humane end of life for everyone by putting first respect for the will of the patient.*)

20. House of Lords Select Committee on Assisted Dying for the Terminally Ill Bill. *Minutes of Evidence; Examination of Witnesses*. 13 January, 2005 (Questions 1860 - 1879): Professor Bart van den Eynden (Q1862)

[<http://www.publications.parliament.uk/pa/ld200405/ldselect/ldasdy/86/5011313.htm>] (Accessed 2005-10-25).

21. Here, again, the statement differs from the earlier position of the Federation, as described by Broeckaert and Janssens. The FPVZ had successfully argued that the role of the second physician in the euthanasia process be expanded from simply confirming the incurability of the patient's illness to confirming that the patient's mental or physical suffering cannot be alleviated, but had not suggested that a member of the palliative team would act as the second physician processing a euthanasia request.

22. The Federation argues that direct participation would completely contradict "the emphasis we wish to place on the continuity of the healthcare and emancipatory concern incorporated into the organisation of Flemish palliative care: the basic principle that organised palliative care exists to inform and to support and not to act in the place of normal healthcare." The "emancipatory concern" appears to be the desire to avoid "pseudo-choices" for euthanasia - decisions that are not actually freely made because the patient has been given no clear palliative alternative and is thus constrained in his choices. If so, it is not clear how this relates to what follows.

23. Rien Janssens, Hen ten Have, David Clark, Bert Broeckaert et al., "Palliative Care in Europe. Towards a more comprehensive understanding." *European Journal of Palliative Care* 8 (2001): p. 20-23. Cited in Broeckaert, B. Janssens, R. "Palliative Care and Euthanasia: Belgian and Dutch Perspectives." p.20-21 *Ethical Perspectives* 9/2-3 (June - September - 2002) 156 - 176 [http://www.kuleuven.ac.be/ep/page.php?LAN=E&FILE=ep_detail&ID=33&TID=57] (Accessed 2005-10-27).

24. *World Health Organization Definition of Palliative Care*. [<http://www.who.int/cancer/palliative/definition/en/print.html>] (Accessed 2005-10-13).

25. Doyle D, Hanks G, MacDonald N. *Oxford Textbook of Palliative Medicine*. Oxford University Press, 1993. Quoted at [<http://64.85.16.230/educate/content/elements/oxforddefinition.html>] (Accessed 2005-10-13).

26. American Academy of Hospice and Palliative Medicine Position Statements: *Comprehensive End-of-Life Care and Physician-Assisted Suicide*. Approved by the Board of Directors, June 25, 1997. [<http://www.aahpm.org/positions/suicide.html>] (Accessed 2005-10-13).

27. Somerville, Margaret, *Death Talk: The Case against Euthanasia and Physician Assisted Suicide*. Montreal: McGill-Queen's University Press, 2001, p. 124, quoting T. Quill, "The Case for Euthanasia," "Searching for the 'Soul' of Euthanasia," 11th International Congress on Care of the Terminally Ill, Montreal, 1996.

28. *Organ Trade GP suspended*. BBC News, 15 October, 2002 [<http://news.bbc.co.uk/1/hi/health/2329447.stm>] (Accessed 2004-01-06).

See also Dyer, Owen, "Organ trafficking prompts UK review of payments for donors". *British Medical Journal* 2002;325:924 (26 October)

29. Wet betreffende de rechten van de patiënt, Art.8.§ 2 [Law Regarding the Rights of the Patient, Art. 8.§ 2] Selected sections in English and Dutch at [http://www.consciencelaws.org/Examining-Conscience-Background/Euthanasia/BackEuthanasia15.html]
30. Murphy, Sean, *Planned Parenthood and "Anti-Choice" Rhetoric: A response to "Planned Parenthood Targets 'Anti-choice' Docs"* [Mario Toneguzzi, *Calgary Herald*, August 19, 2004] [http://www.consciencelaws.org/Project/Conscience-Archive/Commentary/Conscience-Commentary-2004-07-to-12.html#Planned Parenthood and Anti-Choice Rhetoric]
31. Jay Budziszewski, "Handling Issues of Conscience". *The Newman Rambler* (Spring/Summer 1999, Vol. 3, No. 2). [http://www.consciencelaws.org/Examining-Conscience-Issues\Ethical\Articles\Ethical07.html]
32. House of Lords Select Committee on Assisted Dying for the Terminally Ill Bill. *Minutes of Evidence; Examination of Witnesses*. 13 January, 2005 (Questions 1860 - 1879): Professor Bart van den Eynden (Q1861) [http://www.publications.parliament.uk/pa/ld200405/ldselect/ldasdy/86/5011313.htm] (Accessed 2005-10-25)
33. Document quoted in Project Report 2004-01 (Restricted circulation)
34. Benson, Iain, T. *"Autonomy", "Justice" and the Legal Requirement to Accommodate the Conscience and Religious Beliefs of Professionals in Health Care* (Revised March 2001) [http://www.consciencelaws.org/Examining-Conscience-Legal\Legal04.html]
35. Charles, C., Gafni, A., Whelan, T., 1997. *Shared decision making in the medical encounter: what does it mean? (or, it takes at least two to tango)*. *Social Science and Medicine* 44, 681-692. Charles, C., Gafni, A., Whelan, T., 1999. In a later paper on the same subject, the authors stated: "If a physician cannot, in good conscience, endorse the patient's preference, then there is no agreement on the decision to implement even though the deliberation process was shared . . . patients face constraints in that their preferences . . . can only be implemented if a physician agrees to do so. On the other hand . . . A patient turned down by one physician can make the same treatment request to another . . . A refusal from the first physician does not preclude her from receiving the desired services from the second." *Shared decision-making in the physician-patient encounter: revisiting the shared treatment decision-making model*. *Social Science and Medicine* 49, 651-661

The Belgian Act on Euthanasia

28 May, 2002

Chapter VI: Special Provisions

Section 14

The request and advance directive referred to in Sections 3 and 4 of this Act are not compulsory in nature.

No physician may be compelled to perform euthanasia.

No other person may be compelled to assist in performing euthanasia.

Should the physician consulted refuse to perform euthanasia, then he/she must inform the patient and the persons taken in confidence, if any, of this fact in a timely manner, and explain his/her reasons for such refusal. If the refusal is based on medical reasons, then these reasons are noted in the patient's medical record.

At the request of the patient or the person taken in confidence, the physician who refuses to perform euthanasia must communicate the patient's medical record to the physician designated by the patient or person taken in confidence.

Law Regarding the Rights of the Patient (Belgium)

DUTCH ORIGINAL

ENGLISH TRANSLATION

HOOFDSTUK II. - Definities en toepassingsgebied

CHAPTER II.

Art. 2. Voor de toepassing van deze wet moet worden verstaan onder :

Art. 2. For the purposes of this Act, the following definitions shall apply:

1° patiënt : de natuurlijke persoon aan wie gezondheidszorg wordt verstrekt, al dan niet op eigen verzoek;

1° patient: the natural person for whom healthcare is provided, whether or not at their own request;

2° gezondheidszorg : diensten verstrekt door een beroepsbeoefenaar met het oog op het bevorderen, vaststellen, behouden, herstellen of verbeteren van de gezondheidstoestand van een patiënt of om de patiënt bij het sterven te begeleiden;

2° healthcare: services provided by a professional practitioner with the aim of fostering, assessing, preserving, restoring or improving the state of health of a patient or of attending to the patient when dying;

Art. 3. § 1. Deze wet is van toepassing op privaatrechtelijke en publiekrechtelijke rechtsverhoudingen inzake gezondheidszorg verstrekt door een beroepsbeoefenaar aan een patiënt.

Art. 3. 1. This Act shall apply to legal conduct in private and public law with regard to healthcare provided to a patient by a professional practitioner.

Art. 4. In de mate waarin de patiënt hieraan zijn medewerking verleent, leeft de beroepsbeoefenaar de bepalingen van deze wet na binnen de perken van de hem door of krachtens de wet toegewezen bevoegdheden. In het belang van de patiënt pleegt hij desgevallend multidisciplinair overleg

Art. 4. Insofar as the patient lends his cooperation to such, the professional practitioner shall observe the provisions of this Act within the limitations of the rights assigned him by or pursuant to the Act. He shall engage in multi-disciplinary consultations where appropriate in the interests of the patient.

HOOFDSTUK III. - Rechten van de patiënt

CHAPTER III. - Rights of the patient

Art. 5. De patiënt heeft, met eerbiediging van zijn menselijke waardigheid en zijn zelfbeschikking en zonder enig onderscheid op welke grond ook, tegenover de beroepsbeoefenaar recht op kwaliteitsvolle dienstverstrekking die beantwoordt aan zijn behoeften.

Art. 5. The patient shall have the right to the provision of a quality service by the professional practitioner, in accordance with his needs and with respect for his human dignity and self-determination, without any discrimination on any grounds whatsoever.

Art. 6. De patiënt heeft recht op vrije keuze van de beroepsbeoefenaar en recht op wijziging van deze keuze behoudens, in beide gevallen, beperkingen opgelegd krachtens de wet.

Art. 6. The patient shall have the right to the freedom of choosing the assigned professional practitioner and of changing such choice, subject in both cases to the limitations set out in the Act.

Art. 7. § 1. De patiënt heeft tegenover de beroepsbeoefenaar recht op alle hem betreffende informatie die nodig is om inzicht te krijgen in zijn gezondheidstoestand en de vermoedelijke evolutie ervan.

Art. 7. 1. The patient shall have the right to obtain from the professional practitioner all information concerning himself that is necessary to gain an insight into his own state of health and how it is expected to evolve.

Law Regarding the Rights of the Patient (Belgium)

DUTCH ORIGINAL

Art. 8. § 1. De patiënt heeft het recht om geïnformeerd, voorafgaandelijk en vrij toe te stemmen in iedere tussenkomst van de beroepsbeoefenaar.

Deze toestemming wordt uitdrukkelijk gegeven behalve wanneer de beroepsbeoefenaar, na de patiënt voldoende te hebben geïnformeerd, uit de gedragingen van de patiënt redelijkerwijze diens toestemming kan afleiden.

Op verzoek van de patiënt of van de beroepsbeoefenaar en met de instemming van de beroepsbeoefenaar of van de patiënt, wordt de toestemming schriftelijk vastgelegd en toegevoegd aan het patiëntendossier.

§ 2. De inlichtingen die aan de patiënt verstrekt worden, met het oog op het verlenen van diens toestemming bedoeld in § 1, hebben betrekking op het doel, de aard, de graad van urgentie, de duur, de frequentie, de voor de patiënt relevante tegenaanwijzingen, nevenwerkingen en risico's verbonden aan de tussenkomst, de nazorg, de mogelijke alternatieven en de financiële gevolgen. Ze betreffen bovendien de mogelijke gevolgen ingeval van weigering of intrekking van de toestemming, en andere door de patiënt of de beroepsbeoefenaar relevant geachte verduidelijkingen, desgevallend met inbegrip van de wettelijke bepalingen die met betrekking tot een tussenkomst dienen te worden nageleefd.

HOOFDSTUK VI. - Wijzigende- en slotbepalingen

Art. 17novies. Ieder ziekenhuis leeft, binnen zijn wettelijke mogelijkheden, de bepalingen na van de wet van 22 augustus 2002 betreffende de rechten van de patiënt wat betreft de medische, verpleegkundige en andere gezondheidszorgberoepsmatige aspecten in zijn rechtsverhoudingen jegens de patiënt. Bovendien waakt ieder ziekenhuis erover dat ook de beroepsbeoefenaars die er niet op basis van een arbeidsovereenkomst of een statutaire benoeming werkzaam zijn, de rechten van de patiënt eerbiedigen.

ENGLISH TRANSLATION

Art. 8. 1. The patient shall have the right to exercise his informed, prior and free consent in any intervention by the professional practitioner.

This consent shall be given expressly, excepting if the professional practitioner, after having informed the patient sufficiently, can reasonably interpret the patient's conduct as indicating their consent.

On request of either the patient or the professional practitioner and with the assent of either the professional practitioner or the patient, the consent shall be confirmed in writing and included in the patient dossier.

2. The information provided to the patient with the aim of obtaining their consent as intended under 1, shall concern the purpose, the nature, the degree of urgency, the duration, the frequency, the contra-indications, adverse reactions and risks for the patient in connection with the intervention, the aftercare, the possible alternatives and the financial consequences. Moreover, they shall concern the possible consequences in the event that consent is withheld or withdrawn and other clarifications that the patient or the professional practitioner consider relevant, including, where appropriate, the provisions of the Act that are to be observed in respect of an intervention.

CHAPTER VI.

Art. 17h Within their statutory capabilities, all hospitals shall observe the provisions of the Act of 22nd August concerning the rights of the patient in respect of medical, nursing and other professional healthcare-related aspects in their legal conduct vis-à-vis their patients. Furthermore, all hospitals shall also monitor the professional practitioners who are not engaged on the basis of a contract of employment or a statutory appointment, to ensure that the rights of the patient are respected.

Policy Statement on End of Life Decisions and Euthanasia

FLEMISH ORIGINAL

Wetenschappelijk e Vereniging van Vlaamse Huisartsen
Academisch Centrum voor Huisartsgeneeskunde van de Katholieke Universiteit Leuven
Vakgroep Huisartsgeneeskunde van de Universiteit Gent

Persconferentie: Brussels - 4 december 2003

Stellingen

1. Stervensbegeleiding en alle mogelijke hiermee geassocieerde medische beslissingen behoren tot het takenpakket van de huisarts
2. Euthanasie is één van de mogelijke keuzes bij stervensbegeleiding, en dient gekaderd en ingebed te worden in een palliatieve totaalzorg die de individuele zorg overstijgt
3. De zorgregio's moeten over stervensbegeleiding multidisciplinaire navorming en opleiding organiseren. Wij engageren ons om dit wetenschappelijk en didactisch te begeleiden in samenwerking met de Federatie Palliatieve Zorg Vlaanderen en het LEIF-artsenforum. Zo willen wij vermijden dat polariserende groepen ontstaan met eigen opleidingen en invullingen.
4. Wij verzetten ons tegen de oprichting van euthanasieteams of euthanasiecentra. Artsen moeten ondersteund en begeleid worden en strategieën moeten ontwikkeld worden wanneer zij om praktische of ethische redenen niet kunnen ingaan op een euthanasieverzoek van hun patiënt.
5. Zowel de andere als de tweede te raadplegen arts in het kader van de euthanasiebeslissing moeten zeer deskundig zijn op het gebied van palliatieve totaalzorg.
6. Elke arts heeft het recht euthanasie of een andere levenseindebeslissing te beschouwen als niet strokend met zijn persoonlijke ethiek. Deze arts is dan verplicht dit tijdig en duidelijk aan zijn patiënt mee te delen en te zorgen voor een soepele doorverwijzing.

Het artsenkorps is niet voorbereid op de toepassing van de recente wetgevingen in verband met patiëntenrechten en euthanasie. De grondige persoonlijke reflectie van de arts over zijn houding hieromtrent dient gevoed en ondersteund door collegiaal overleg.

ENGLISH TRANSLATION

The Belgian Association of General Practitioners

The Academy at the Catholic University of Leuven
The Academy for Knowledge at the University of Ghent

Press Conference: Brussels - 4 December 2003

Positions

1. The responsibilities of the general practitioner include aid in dying and everything connected thereto.
2. Euthanasia is one of the possible choices of dying and should be enclosed in the total palliative care encompassing care of the individual.
3. The care regions must organize multidisciplinary teams and training for the dying. To prevent polarization within our own disciplines, we are collaborating with the Flemish Palliative Care Federation and LEIF forum for medical doctors.
4. We are against the formation of euthanasia teams and centres. GP's have to be given guidance and develop strategies to respond to a request for euthanasia by a patient, when they disagree with it for ethical or practical reasons.
5. Both the GP and the second physician who are to be consulted in the euthanasia decision should be very well versed in total palliative care.
6. Every physician has the right to refuse euthanasia or any other end of life decision if it clashes with his personal ethics. However, this physician must give timely notice to his patient of this and refer the patient to another physician with a different view.

Physicians have not been prepared for the implementation of the recent legislation in connection with patients rights and euthanasia. The thorough personal reflection of the physician about his attitude toward this is nourished and supported through collegial thought.

Policy Statement on End of Life Decisions and Euthanasia

FLEMISH ORIGINAL

De Wetenschappelijke Vereniging van Vlaamse Huisartsen wil het artsenkorps in dit proces van reflectie wetenschappelijk begeleiden. De vereniging wil dit concretiseren door middel van onderzoek en door het organiseren van navorming[1], opleiding en training over de besluitvorming bij alle levenseindebeslissingen.

Zij wil dit doen in nauwe samenwerking met de andere huisartsenorganisaties en met de Federatie voor Palliatieve Zorg Vlaanderen en het Leifartsenforum. Zij wil vermijden dat polariserende groepen ontstaan met eigen opleidingen en invullingen. Zij wil mee zoeken naar een optimalisering van de begeleiding bij het levenseinde waarin aanbevelingen en wetten erkend en toegepast worden in een open sfeer van continue reflectie en toetsing.

De huisartsenkringen hebben hier een belangrijke taak. De zorgregio is het niveau waarop alles in verband met stervensbegeleiding dient geïnventariseerd te worden en waarop de noodzakelijke navorming bij voorkeur multidisciplinair dient georganiseerd te worden. Wij willen dan ook de palliatieve netwerken uitnodigen zich op deze evolutie positief voor te bereiden.

Handelingen aan het levenseinde behoren tot de taak en functie van de huisarts. De thuisbegeleiding van een patiënt met een fatale prognose gebeurt best door de huisarts. Multidisciplinaire samenwerking en overleg zijn echter noodzakelijk in de fase die de dood voorafgaat en waarin belangrijke beslissingen moeten genomen worden.

Dit vereist ook dat de andere disciplines, ook deze op de tweede lijn, de huisarts erkennen in zijn specifieke taak en bereid zijn tot die multidisciplinaire samenwerking. Ondersteuning vragen van de multidisciplinaire thuiszorgequipes voor palliatieve zorg is in de regel aangewezen omdat niet alle artsen voldoende vertrouwd zijn met de mogelijkheden en de specifieke doelstellingen van palliatieve zorg.

ENGLISH TRANSLATION

The Belgian Association of General Practitioners wants to accompany the physicians corps in this trial of reflection. The association want to concretize this through means of investigation and through the organizing of continuing medical education [1] and training in end of life over the decision-making.

We want to do this specifically with other general practitioners organizations and with the Flemish Palliative Care Federation and the LEIF forum for medical doctors. We want to avoid polarization within our own discipline. We want to seek to an optimization of the care at end of life in which research findings are applied in an open atmosphere of continuous reflection and review.

The general practitioners circles have here an important task. The care region is the level at which everything in connection with care of the dying should be available and at which the preferred multidisciplinary approach is organized. We also want to encourage the positive evolution of palliative networks.

The GP has an important task at the end of life as the home care of the patient with a fatal prognosis is handled by the GP. However, multidisciplinary co-operation and deliberation are necessary in the phase preceding death, during which important decisions must be made.

This is also required of other disciplines, but the general practitioner must recognize his specific task and be ready to cultivate that multidisciplinary cooperation. Asking for the support of multidisciplinary groups is, as a rule, indicated, because not all physicians are sufficiently versed in the possibilities and specific objectives of palliative care.

Policy Statement on End of Life Decisions and Euthanasia

FLEMISH ORIGINAL

Alle mogelijkheden moeten eerst met de patiënt besproken worden zodat hij goed geïnformeerd ook kan kiezen voor euthanasie. Psychologische en/ of spirituele begeleiding, ondersteuning van de mantelzorg, verzorging in een palliatieve eenheid zijn opties die onderzocht moeten worden. Dit laatste vraagt een bijzondere en wederzijdse inzet van de huisarts en de specialist om transmuraal goed samen te werken.

Hoewel heel wat patiënten nog steeds de “colloque singulier” verkiezen moet een arts overtuigd zijn van de meerwaarde van een multidisciplinaire aanpak. Ook de patiënt die in de fase van ontkenning blijft vastzitten, moet kunnen rekenen op respect en begrip voor deze houding. Het multidisciplinaire en open overleg tussen de verschillende betrokken hulpverleners zal hen helpen om ook in deze moeilijke situatie een aangepaste zorg en ondersteuning te verlenen.

Om dit op een kwaliteitsvolle wijze te doen is het aanvaarden van de autonomie van de patiënt een eerste vereiste. Afstappen van het concept van de ‘weldoende’ arts die beslist over leven of dood is voor sommige artsen erg confronterend en verwarrend. Het nieuwe concept waarin de patiënt zelf beslist over zijn gezondheid, ziekte en manier van sterven vraagt van de arts een aangepaste attitude en een enorme communicatievaardigheid.

Communicatie en overleg vormen de kern van het ‘informed consent’, de ‘shared decision making’ en het eventueel opstellen van een “informatie- en communicatiecontract” waarin arts en patiënt afspreken tot op welke hoogte de patiënt wenst ingelicht te worden en wie, wanneer de patiënt zelf niet meer verder wil geïnformeerd worden zijn vertrouwenspersoon is waarmee de arts verdere afspraken kan maken.

Deze vaardigheid is op de dag van vandaag zeker nog niet algemeen verworven in het medisch korps. Artsen moeten in hun continue navorming hieraan de nodige aandacht besteden. Ook heel wat patiënten zijn nog niet vertrouwd met deze nieuwe visie op de artspatiënt relatie en kunnen hierop onwennig reageren en zich zelfs verontrust voelen.

ENGLISH TRANSLATION

All possibilities must first be discussed with the patient so that he is well-informed and can opt for euthanasia. Psychological and/ or spiritual care are desirable options in unified palliative care. These last requires special and mutual effort of the general practitioner and the specialist, who must work well together.

Although many patients still prefer one-on-one relationship, physicians must be convinced of the greater value of a multidisciplinary approach. Moreover, the patients who are stuck in denial must be able to count on respect and understanding of their attitude. The multidisciplinary approach and shared understanding among the different relief workers involved will also help them help to provide appropriate care and support.

Team members must acknowledge that acceptance of the autonomy of the patient is a first requirement. Giving up the conception of the paternalistic physician who makes life and death decisions is very confusing and challenging for some physicians. The new conception in which the patient himself makes decisions about his health, illness and manner of dying demands adaptive attitudes and enormous communication skills on the part of physicians.

Communication and deliberation are essential to ‘informed consent’ and ‘shared decision making’, and may include the use of an “information and communication contract” in which physician and patient agree upon a trusted person who will be the GP’s contact once the patient is personally unable to participate.

This skill is needed in the medical profession but not always acquired. Physicians must attend to this as part of their continuing medical education. Moreover, many patients can react uncomfortably and even feel alarmed because they are not yet have accustomed to this new view of the physician patient relationship.

Policy Statement on End of Life Decisions and Euthanasia

FLEMISH ORIGINAL

Hoe een patiënt denkt over euthanasie moet vooraf besproken worden en geregistreerd in het medisch dossier.

De huisarts als de zorgverlener die de levensloop van de patiënt begeleidt is goed geplaatst om de wensen van de patiënt over zijn levenseinde te bespreken, te bewaken en te registreren in het medisch dossier. De arts moet dit gesprek in bepaalde gevallen zelf initiëren om te vermijden dat minder geïnformeerde patiënten of minder communicatievaardige patiënten hun recht op een euthanasievraag wordt ontzegd. In de palliatieve fase worden deze gegevens overgebracht naar het palliatief zorgdossier.

Euthanasie kan een mogelijke keuze van stervensbegeleiding zijn, gekaderd en ingebed in een palliatieve totaalzorg. Hieruit volgt dat het oprichten van euthanasieteams en centra voor euthanasie dient te worden vermeden. Het is onze overtuiging dat de voor de toepassing van euthanasie vereiste andere en tweede arts zeer deskundig moet zijn op het gebied van palliatieve zorg en meer specifiek op het gebied van de mogelijke medische beslissingen aan het levenseinde. De artsen verbonden aan de multidisciplinaire thuiszorgequipes palliatieve zorg komen hiervoor zeker in aanmerking.

Wanneer euthanasie niet strookt met de persoonlijke ethiek van de arts moet hij dit tijdig en duidelijk aan zijn patiënt meedelen. Samen kunnen zij dan een andere behandelende arts voor de patiënt zoeken. Het is aan de huisartsenkringen om binnen een zorgregio hiervoor passende strategieën te ontwikkelen en aan te bieden.

ENGLISH TRANSLATION

What a patient thinks about euthanasia should be discussed and recorded in his medical file in advance.

The attending GP is well placed to understand the medical history of the patient, to discuss end of life decisions and record the information in the medical file. In some cases the physician must initiate these discussions to ensure that less well-informed patients are not denied their right to choose euthanasia. In the palliative care phase these discussions should be recorded in the palliative care file.

Euthanasia is a possible choice at the end of life included in a total package of palliative care. It follows that euthanasia teams and centres for euthanasia should not be set up. It is our conviction that the second physician required must have specialized knowledge about palliative care and end of life decisions. Physicians involved in multidisciplinary teams should be consulted.

When the physician does not agree with euthanasia because of his personal ethics, he must give clear and timely notice of this to his patient. They can then work together to find a physician with a different view. GP circles within a care region should develop suitable strategies for this purpose.

Dealing with Euthanasia & Other Forms of Medically Assisted Death Flemish Palliative Care Federation (September, 2003)

DUTCH ORIGINAL

Onderstaande tekst verwoordt de visie van de Federatie op euthanasie en andere vormen van medisch begeleid sterven zoals bekendgemaakt op het Symposium van 6 september 2003 "Beslissingen op de grens van leven en dood". Het is mogelijk dat deze visie in de toekomst nog wordt bijgesteld.

ENGLISH TRANSLATION

The text below reflects the vision of the Federation with regard to euthanasia and other forms of medically-assisted death, as announced at the Symposium on 6th September 2003 "Decisions on the border between life and death". This vision may be subject to future amendment.

Het doel van palliatieve zorg is de best mogelijke levenskwaliteit te bieden aan de ongeneeslijk zieke patiënt en zijn naastbestaanden. Om dit doel te bereiken moeten er niet zelden delicate medisch-ethische beslissingen genomen worden. Is een ziekenhuisopname nog aangewezen? Of is het beter de patiënt zijn of haar laatste maanden in de vertrouwde omgeving te laten doorbrengen? Hoever kunnen we gaan in onze pijn- en symptoomcontrole? Wat doen we met voeding en vocht als normaal eten en drinken onmogelijk wordt? Wanneer verwordt een levensverlengende behandeling tot therapeutische hardnekkigheid?

... De ervaring leert en wetenschappelijk onderzoek toont aan dat zorgverleners veel vaker met deze moeilijke vragen te maken hebben dan met vragen om euthanasie. Het is van het grootste belang dat ook bij deze vragen, waarvoor er geen uitgewerkte, wettelijke procedures zijn voorzien, de grootst mogelijke zorgvuldigheid wordt beoogd. Ook hier moet de stem van de patiënt een bepalende rol spelen. Ook hier zijn gespecialiseerd advies en deskundige ondersteuning aangewezen. Voor dit advies en deze ondersteuning kan iedere zorgverlener bij de palliatieve equipes van de eigen regio of instelling terecht. Niettegenstaande haar inbedding in een veel omvangrijker geheel van medisch-ethische beslissingen verdient euthanasie, omwille van haar uitzonderlijke karakter, onze bijzondere aandacht. Van bij het begin van het euthanasiedebat heeft de Federatie Palliatieve Zorg Vlaanderen ervoor gekozen een open en constructieve dialoog aan te gaan met de politieke wereld.

The objective of palliative care is to provide terminally ill patients and their relatives with the best possible quality of life. In order to achieve this objective, delicate medical-ethical decisions often need to be made. Is admittance to hospital still required? Or would it be better to allow the patient to spend his or her final months in familiar surroundings? To what extent should we control pain and other symptoms? What should we do with foods and liquids if normal eating and drinking become impossible? When does life-sustaining treatment turn into therapeutic persistence?

... Experience teaches, and scientific research shows, that carers are confronted with these difficult issues a lot more often than with requests for euthanasia. It is vitally important that the greatest possible care is also taken with these issues, for which no legal procedures have been devised. Likewise, the patient's say must play a decisive part in these cases; and specialist advice and professional support is also required. For advice and support, carers can contact the palliative teams from their local region or institution. Despite the embedding of euthanasia in a considerably larger realm of medical-ethical decisions, its exceptional character causes it to merit our particular attention. From the start of the debate on euthanasia, the Flemish Palliative Care Federation has chosen to have an open and constructive dialogue with the political world.

Dealing with Euthanasia & Other Forms of Medically Assisted Death Flemish Palliative Care Federation (September, 2003)

DUTCH ORIGINAL

Het in voege treden van de euthanasiewet, nu bijna één jaar geleden, heeft binnen de Federatie en haar diverse geledingen het denkproces omtrent euthanasie en andere vormen van medisch begeleid sterven alleen maar versterkt. Bij heel wat zorgverleners blijken rond euthanasie en de euthanasiewet nog steeds heel wat vragen en onzekerheden te bestaan. Als overkoepelend orgaan van de Vlaamse palliatieve zorg-initiatieven leek het ons daarom aangewezen, mede ook met het oog op de voorziene evaluatie van de euthanasiewet, de volgende aandachtspunten naar voren te schuiven.

Uitgangspunt: geen polarisatie, maar dialoog en respect

1. Palliatieve zorg en euthanasie zijn alternatieven noch tegenpolen. Wanneer een arts bereid is het euthanasieverzoek in te willigen van een patiënt die ondanks de beste zorgen ondraaglijk blijft lijden, dan ontstaat geen breuk tussen de eerder door de arts gegeven palliatieve zorg en de nu door hem toegepaste euthanasie, integendeel. Euthanasie maakt in voorkomend geval deel uit van de palliatieve zorg waarmee de arts en het verzorgend team de patiënt en zijn/haar naasten omringt”

2. Dialoog en respect zijn sleutelwoorden in het omgaan met euthanasie en andere vormen van medisch begeleid sterven. Een eerlijke en interactieve houding waarin men met de patiënt op weg gaat, in alle openheid maar ook in het grootste respect voor zijn/haar levensovertuiging en deze van zichzelf en de andere zorgverleners, biedt de beste kansen voor een menswaardig sterven.

Zorgverleners hebben hierbij het volste recht eigen ethische grenzen te stellen, al wordt verwacht dat ze deze grenzen eerlijk, duidelijk en vooral ook tijdig aangeven.

ENGLISH TRANSLATION

The Belgian Euthanasia Act, which came into force almost a year ago, has only served to strengthen the thought process relating to euthanasia and other forms of medically-assisted death within the Federation and its various sections. Many carers still have a lot of questions and uncertainties with regard to euthanasia and the Euthanasia Act. As umbrella organisation for the Flemish palliative care initiatives, it seemed appropriate to us to focus more attention on the following points, partly also with a view to the forthcoming evaluation of the Euthanasia Act.

1. Palliative care and euthanasia are neither alternatives nor opposites. When a doctor is prepared to accede to the euthanasia request of a patient who continues to find life unbearable despite the best treatment, then there is no gap between the palliative care given previously by the doctor and the euthanasia he applies now; on the contrary. In such a case, euthanasia forms part of the palliative care with which the doctor and the care team surround the patient and his or her nearest.

2. Dialogue and respect are key words when dealing with euthanasia and other forms of medically-assisted deaths. An honest and interactive relationship with the patient, completely open and with the greatest respect for the beliefs of the patient, their own beliefs and those of other carers, provides the best chances for a dignified death.

In this respect, carers are fully entitled to set their own ethical limits, but are expected to make these known clearly, honestly and sufficiently in advance.

Dealing with Euthanasia & Other Forms of Medically Assisted Death Flemish Palliative Care Federation (September, 2003)

DUTCH ORIGINAL

Verantwoord omgaan met een euthanasieverzoek: begrip, deskundigheid en interdisciplinariteit

3. Mensen vragen niet om euthanasie vanuit één of andere morbide doodswens, omdat ze altijd al zo graag dood wilden, maar omdat op een bepaald moment in hun ziekteproces voor hen het lijden en daardoor het leven zelf ondraaglijk is geworden. Diverse factoren kunnen hier, vaak in combinatie, een doorslaggevende rol spelen: de angst voor wat komen gaat, ademhalingsproblemen, ontluistering, fysieke pijn, het verlies van controle, het steeds zwakker en totaal afhankelijk worden, ... Een euthanasievraag heeft aldus bij uitstek te maken met een bestaand of verwacht gebrek aan levenskwaliteit, veroorzaakt door het lichamelijke, psycho-sociale en/of geestelijke lijden van de patiënt. Het is dan ook de taak van de zorgverlener die om euthanasie wordt gevraagd in meerdere open en diepgaande gesprekken (cfr. Art. 3, §2, 2° euthanasiewet) met de patiënt zicht te krijgen op het waarom van zijn/haar vraag tot levensbeëindiging: wat is het precies dat maakt dat het leven voor hem of haar niet langer uit te houden is?

4. Gezien het delicate, onomkeerbare en ingrijpende karakter van euthanasie is het van het grootste belang dat euthanasie slechts wordt toegepast wanneer er sprake is van een lijden 'dat niet gelenigd kan worden' (Art. 3, §1 euthanasiewet), van een situatie 'waarvoor er geen redelijke andere oplossing is' (Art. 3, §2, 1° euthanasiewet). Vandaar dat de zorgverlener met de patiënt dient na te gaan of het 'normale' medische handelen niet in staat is de lichamelijke, psycho-sociale en/of geestelijke pijn die aan de oorsprong ligt van zijn/haar euthanasieverzoek te verlichten. Wanneer een patiënt bijvoorbeeld om euthanasie vraagt omdat de lichamelijke pijn niet te harden is, dan kan euthanasie pas worden overwogen wanneer vaststaat dat zelfs een geoptimaliseerde pijntherapie niet helpt.

ENGLISH TRANSLATION

Dealing responsibly with a request for euthanasia: understanding, expertise and interdisciplinarity

3. People do not request euthanasia because of some morbid death wish, or because they have always wanted to die, but because, at some point during their sickness, their suffering, and therefore life itself, becomes unbearable. Various factors, often in combination, can play a decisive role in this: fear of what will happen, respiratory difficulties, humiliation, physical pain, loss of control, increasing weakness and total dependence on others, etc. A request for euthanasia is always associated with an actual or expected decline in the quality of life, as a result of the patient's physical, psycho-social and/or mental suffering. It is therefore the responsibility of the carer, who receives a request for euthanasia, to conduct several open and in-depth discussions (cfr. Art. 3, §2, 2° Euthanasia Act) with the patient in order to understand the reasons why he or she has requested an end to life: what is it exactly that makes his or her life unbearable?

4. In view of the delicate, irreversible and radical nature of euthanasia, it is vitally important that euthanasia only be performed in cases where there is evidence of suffering 'which cannot be alleviated' (Art. 3, §1 Euthanasia Act), and a situation 'for which there is no other reasonable solution' (Art. 3, §2, 1° Euthanasia Act). Therefore, the carer and patient should first check whether 'normal' medical treatment might not be able to ease the physical, psycho-social and/or mental pain at the root of the patient's request for euthanasia. If a patient asks for euthanasia because he or she cannot tolerate the physical pain, it should only be considered once it has been established that even optimised pain therapy cannot help.

Dealing with Euthanasia & Other Forms of Medically Assisted Death Flemish Palliative Care Federation (September, 2003)

DUTCH ORIGINAL

Een verzoek om levensbeëindiging, ook al is het nog vaag en nauwelijks uitgesproken, dient dan ook steeds de aanleiding te zijn tot een evaluatie en zo nodig bijsturing van de eigen zorgpraktijk. Wat kunnen we doen om onze zorg nog meer af te stemmen op de noden van de patiënt? Is het lijden van de patiënt inderdaad niet te lenigen? Of stoten we gewoon op de grenzen van het eigen kunnen en is daarom gespecialiseerd advies noodzakelijk?

5. Palliatieve zorg is, omdat ze de mens in zijn totaliteit benadert, per definitie interdisciplinair. Een arts die om euthanasie wordt verzocht kan zich in zijn/haar zorg voor deze patiënt en zijn/haar beslissing al dan niet in te gaan op het verzoek van de patiënt dan ook nooit als eenling gedragen. Een verantwoorde omgang met een euthanasieverzoek houdt steeds een interdisciplinaire benadering in. Er zijn enerzijds reeds de veelheid, diversiteit en complexiteit van motieven die aan een verzoek tot levensbeëindiging ten grondslag kunnen liggen en de eigen inzichten die de verschillende zorgverleners terzake kunnen bieden. Men denke bijvoorbeeld aan de verpleegkundigen die vaak letterlijk en figuurlijk dicht bij de patiënt staan en daardoor vaak heel goed weten wat er schort (boven, punt 3.).

En anderzijds is een gespecialiseerde inbreng vanuit diverse disciplines vaak noodzakelijk om het lijden van de patiënt te lenigen (boven, punt 4.).

De palliatieve equipe: ook bij een euthanasieverzoek de aangewezen partner

6. Wanneer een hulpverlener om euthanasie wordt verzocht is het, omwille van het aangegeven grote belang van gespecialiseerde deskundigheid en interdisciplinariteit, meer dan aangewezen de palliatieve equipe van de eigen instelling of de plaatselijke thuiszorgregio in het overleg te betrekken.

ENGLISH TRANSLATION

A request to end one's life, even if it is still vague and barely expressed, must always initiate an evaluation, and any necessary adjustment of the care given. What can we do to tailor our care more closely to the needs of the patient? Is it really impossible to alleviate the patient's suffering? Or have we reached the limits of our own competence and is specialised advice required?

5. By definition, palliative care is interdisciplinary, because it affects the person as a whole. A physician who receives a request for euthanasia can never act alone when caring for the patient or deciding whether to honour the patient's request. Dealing responsibly with a request for euthanasia always requires an interdisciplinary approach. On the one hand, there are many diverse and complex reasons that can underlie a request to end one's life and the various perspectives that the different carers can provide on the matter. Think of the nurses, for example, who are close to the patient, both literally and figuratively speaking, and therefore have a very good understanding of what the problem is (see point 3 above).

And on the other hand, specialised input from various disciplines is often required in order to alleviate the patient's suffering (see point 4 above).

The palliative team: a suitable partner, also in the case of a euthanasia request

6. Given the important role played by interdisciplinarity and specialist advice, it is strongly recommended for the carer to consult the palliative team from their own institution or local home care organisation whenever they receive a request for euthanasia.

Dealing with Euthanasia & Other Forms of Medically Assisted Death Flemish Palliative Care Federation (September, 2003)

DUTCH ORIGINAL

Het omvattende, sterk uitgebouwde en daardoor unieke netwerk van palliatieve equipes dat ons land kent is immers precies opgericht om de niet zelden problematische levenskwaliteit van ongeneeslijk zieken te verbeteren, om hun lijden, van welke aard ook, in de mate van het mogelijke te lenigen. De expertise, interdisciplinariteit en emancipatorische aanpak eigen aan deze equipes staat garant voor de zorgvuldigheid en werkzaamheid van hun optreden. Wanneer een arts of zorgverlener om euthanasie verzocht wordt stellen deze equipes graag hun palliatieve expertise ter beschikking, niet om betweterig in zijn of haar plaats te treden, maar om te informeren over palliatieve mogelijkheden en om te ondersteunen. Op die manier kunnen tragische schijnkeuzes, die meer te maken hebben met het ontbreken van goede palliatieve zorg dan met een uitdrukkelijke wil het leven te beëindigen, worden vermeden en wordt een keuze voor euthanasie een echte, geïnformeerde keuze. De Federatie Palliatieve Zorg Vlaanderen herhaalt dan ook haar voorstel om in de euthanasieprocedure een voorafgaandelijk palliatief overleg met de palliatieve ondersteuningsquipe van de eigen instelling of het plaatselijke palliatieve netwerk in te bouwen. Een dergelijk overleg is overigens belangrijk bij alle vormen van medisch begeleid sterven. De praktijk leert intussen in elk geval dat veel artsen, vanuit hun terechte bezorgdheid bij een euthanasieverzoek een verantwoorde beslissing te nemen, een belangrijke plaats toekennen aan het overleg met de palliatieve equipe –zoals ze dit ook doen waar het gaat om andere delicate medisch-ethische kwesties aan het levenseinde.

7. Hulpverleners kunnen met al hun vragen rondom het levenseinde terecht bij de palliatieve equipes. Van de palliatieve equipes kunnen zorgverleners en patiënten dan ook niet alleen verwachten dat deze, in de context van een euthanasieverzoek, informeren over eventuele palliatieve alternatieven en palliatieve ondersteuning verlenen waar nodig.

ENGLISH TRANSLATION

The comprehensive, widely expanded and, therefore, unique network of palliative teams in Belgium has been precisely set up to improve the often problematic quality of life experienced by the terminally ill, and to alleviate their suffering as much as possible, whatever its cause may be. The expertise, interdisciplinarity and the emancipatory approach characteristic of these teams ensure that they act carefully and effectively. Whenever a physician or carer receives a request for euthanasia, these teams offer their palliative expertise willingly, not in order to appear pedantic and to take over, but to give information on the palliative options available and to provide support. In this way, the tragedies associated with pseudo-choices, which have more to do with a lack of good palliative care rather than with an express desire to end one's life, can be prevented, making the choice for euthanasia a real, informed decision. The Flemish Palliative Care Federation reiterates its proposal to include a prior palliative consultation with the palliative team from one's own institution or from the local palliative network in the euthanasia procedure. For that matter, this type of consultation is important for all forms of medically-assisted death. In any case, practice has already shown that many physicians, rightly concerned about making a responsible decision when confronted with a euthanasia request, consider consultation with the palliative team to be of vital importance; as is also the case with other delicate medical-ethical issues that arise when the patient reaches the end of his or her life.

7. Carers can address all their questions regarding the end of life to the palliative teams. Therefore, in the context of a euthanasia request, carers and patients can expect the palliative teams to do more than merely inform them about potential palliative alternatives and palliative support where necessary.

Dealing with Euthanasia & Other Forms of Medically Assisted Death Flemish Palliative Care Federation (September, 2003)

DUTCH ORIGINAL

Zorgverleners en patiënten kunnen bij de netwerken en equipes ook terecht voor informatie en ondersteuning die rechtstreeks en specifiek verband houdt met euthanasie en de euthanasiewet. Equipe-artsen kunnen de rol opnemen van de 'andere' of 'tweede' arts in de euthanasieprocedure. Wat men van de georganiseerde palliatieve zorg evenwel niet kan en mag verwachten is dat zij in de plaats gaat treden van de behandelende arts en zij in voorkomend geval in zijn/haar plaats euthanasie gaat uitvoeren. Dit zou volledig in tegenspraak zijn met de nadruk die wij willen leggen op de continuïteit van de zorgverlening en de in de organisatie van de Vlaamse palliatieve zorg ingeschreven emancipatorische bekommernis: het basisprincipe dat de georganiseerde palliatieve zorg er is om te informeren en te ondersteunen en niet om in de plaats te treden van de reguliere zorg"

Vragen aan de overheid

8. In lijn met wat in deze tekst naar voren wordt geschoven vraagt de Federatie Palliatieve Zorg Vlaanderen aan de overheid:

q dat bij de evaluatie van de euthanasiewet (in 2004), het voorstel van een voorafgaandelijke palliatieve consultatie, dat niet alleen gedragen wordt door de Federatie Palliatieve Zorg Vlaanderen, maar ook de steun geniet van de Nationale Raad van de Orde der Geneesheren en eerder reeds kon rekenen op een eenparig positief advies van de Kamercommissie Volksgezondheid, in de wet wordt opgenomen. Deze palliatieve consultatie, een noodzakelijke voorwaarde bij alle vormen van medisch begeleid sterven, dient zo vroeg mogelijk in de stervensbegeleiding te worden ingeschakeld.

ENGLISH TRANSLATION

Carers and patients can also address themselves to the networks and teams for information and support directly related to euthanasia and the Euthanasia Act. Team doctors can take on the role of the 'other' or 'second' doctor in the euthanasia procedure. However, what can and may not be expected from organised palliative care is that it should adopt the role of the practicing doctor and, in the case in point, carry out the euthanasia in his or her stead. This would be completely in contradiction with the emphasis we wish to place on the continuity of the healthcare and emancipatory concern incorporated into the organisation of Flemish palliative care: the basic principle that organised palliative care exists to inform and to support and not to act in the place of normal health care.

Questions for the government

8. In line with the points put forward in this text, the Flemish Palliative Care Federation proposes to the government:

q that during the evaluation of the Euthanasia Act (in 2004), the proposal for a prior palliative consultation, not only supported by the Flemish Palliative Care Federation, but also by the National Council of the Belgian Order of Physicians and which was earlier endorsed unanimously by the Parliamentary Commission for Public Health, be included in the Act. This palliative consultation, a necessary requirement with all forms of medically-assisted death, should take place as early as possible during the euthanasia procedure.

Dealing with Euthanasia & Other Forms of Medically Assisted Death Flemish Palliative Care Federation (September, 2003)

DUTCH ORIGINAL

q dat degelijke en financieel toereikende ondersteunende maatregelen voor de palliatieve equipes (vorming, intervisie, beschikbaarheid personeel, ...) worden uitgewerkt zodat deze equipes in staat worden gesteld op adequate wijze om te gaan met de grote nood aan informatie en ondersteuning, ook wat betreft de diverse delicate medisch-ethische beslissingen aan het levenseinde.

ENGLISH TRANSLATION

q that sound and financially sufficient supportive measures be devised for the palliative teams (training, colleague support groups, availability of staff, etc.) to enable them to deal adequately with the considerable need for information and support, also in relation to the various delicate medical-ethical decisions at the end of the patient's life.

Federatie Palliatieve Zorg Vlaanderen, 6 september
2003

Project Letter to the Belgian Association of General Practitioners 23 July, 2004

Secretariaat, Nancy Denyn
Wetenschappelijke Vereniging van Vlaamse Huisartsen
St.-Hubertusstraat 58,
2600 Berchem,
Belgium

Dear Madam:

I enclose a copy of the Standpunt over medische beslissingen rond het levenseinde en euthanasie issued on 4 December, 2003, with the English translation we have used in reviewing it. The document is of great interest because the Protection of Conscience Project supports freedom of conscience for health care workers who do not wish to participate in procedures to which they object for reasons of conscience. However, the translation is incomplete in some places and only approximates the meaning of the original, so I am writing to ensure that we correctly understand the statement and explore some of the issues it raises.

We are pleased to see that the statement acknowledges that physicians who do not want to participate in euthanasia may decline to do so. We also agree that physicians should give timely notice to patients of their views, and that they should be assisted in developing strategies that will allow them to deal with requests for euthanasia in a manner that is respectful of the patient, and consistent with their own principles. Recording end-of-life discussions in the patients' medical file is very important, especially when there is a conflict between the views of the patient and the views of the physician. The suggestion that an "information and communication contract" could be used in this process is interesting.

However, we have concerns about some parts of the statement, which we now put forward for your consideration. It is possible that some of these reservations are based upon a misunderstanding caused by a mistranslation of the text. If so, correction and clarification would be most welcome.

The first concern is the requirement that a physician who objects to euthanasia is, nonetheless, expected to facilitate the procedure by assisting the patient to find a willing physician. The experience of the Project is that most conscientious objectors would refuse to do so, on the grounds that such collaboration would incur moral responsibility for the act.

The second concern is the stated intention to make euthanasia one of the 'treatment options' in a continuum of palliative care. Outside Belgium and the Netherlands, palliative care is understood to mean relieving the burden of pain and suffering caused by disease, so that patients live comfortably until they die. 'Palliation' specifically excludes euthanasia or assisted suicide. One commonly hears, for example, statements like, "We don't need euthanasia; we need better palliative care." The approach suggested by the statement appears to be a significant departure from this understanding, and would have a great impact on anyone involved in the field.

The third concern is the recommendation that euthanasia should not be treated as a medical specialty, requiring specialist 'teams' and facilities, but should become part of the regular health care system. This would, potentially, require the involvement of anyone involved in health care delivery and

support, thus setting the stage for widespread conflicts of conscience. This problem would be exacerbated by the expectation that conscientious objectors must facilitate patient requests for euthanasia.

Finally, the expectation that physicians must ensure that patients are aware of and able to choose euthanasia is likely to present some problems. We would like to clarify whether or not the signatories to the statement expect or require that physicians communicating this information do so in a manner that portrays euthanasia as a morally neutral or morally legitimate choice.

Sincerely,

(Sean Murphy)
Administrator

Letter from the Belgian Association of General Practitioners to the Project

Dear Sir,

We are delighted that our "Viewpoint regarding medical decisions on the end of life and euthanasia" has attracted your particular attention. We are, therefore, pleased to reply to your comments.

With respect to your first comment: when a physician has conscientious objections to euthanasia, a patient still maintaining his or her request for euthanasia has no other choice than to seek out another doctor. This search is no easy matter for patients who are not so well informed. A free telephone helpline was opened recently with the support of the Belgian government, available for the use of anyone with questions about the end of their life. We believe that a physician with conscientious objections should at least inform the patient of the existence of this helpline in order to avoid the patient being left in the lurch.

With regard to your second comment: in this respect we refer to the text of "Omgaan met euthanasie en andere vormen van medisch begeleid sterven (Dealing with euthanasia and other forms of medically assisted death)", published by the Federatie Palliatieve Zorg Vlaanderen (Flemish Palliative Care Federation) in September 2003:

Palliative care and euthanasia are neither alternatives nor opposites. When a doctor is prepared to accede to the euthanasia request of a patient who continues to find life unbearable despite the best treatment, then there is no gap between the palliative care given previously by the doctor and the euthanasia he applies now; on the contrary. In such a case, euthanasia forms part of the palliative care with which the doctor and the care team surround the patient and his or her nearest.

Further on in the text, we read:

Carers can address all their questions regarding the end of life to the palliative teams. Therefore, in the context of a euthanasia request, carers and patients can expect the palliative teams to do more than merely inform them about potential palliative alternatives and palliative support where necessary. Carers and patients can also address themselves to the networks and teams for information and support directly related to euthanasia and the Euthanasia Act. Team doctors can take on the role of the 'other' or 'second' doctor in the euthanasia procedure. However, what can and may not be expected from organised palliative care is that it should adopt the role of the practicing doctor and, in the case in point, carry out the euthanasia in his or her stead. This would be completely in contradiction with the emphasis we wish to place on the continuity of the healthcare and emancipatory concern incorporated into the organisation of Flemish palliative care: the basic principle that organised palliative care exists to inform and to support and not to act in the place of normal healthcare.

Thus the definition of palliative care we use is broader than the dichotomous vision (palliative care versus euthanasia) that you have formulated. It is our belief that more justice can be done to the patient's perception. We are, indeed, entirely aware - more even, we confidently hope - that this

vision has a strong influence on all concerned in the field.

With respect to the third comment: when we postulate that euthanasia teams or euthanasia centres are not desirable, it is by no means our intention to make euthanasia part of normal healthcare provision. Also, we certainly do not want to compel anyone with conscientious objections to participate in euthanasia. Precisely to the contrary, we argue for loco-regional agreements to be made in order to seek solutions to situations where a conflict arises between a doctor's conscience and a patient's request for euthanasia. Taking into account the fact that the modalities of this euthanasia request are laid down in a democratically voted law.

With regard to the fourth comment: the "Patients' Rights Act" compels doctors in our country to inform patients fully about all possible therapeutic options. In this situation, the doctor is at liberty to inform the patient of his or her personal moral objections. Thus moral neutrality does not exist in respect of a euthanasia request. However, this gives the doctor at least the right to express his or her opinion on whether he or she believes that the patient's choice is or is not morally acceptable.

Project Letter to the Belgian Association of General Practitioners 6 October, 2004

Secretariaat, Nancy Denyn
Wetenschappelijke Vereniging van Vlaamse Huisartsen
St.-Hubertusstraat 58,
2600 Berchem,
Belgium

Dear Madam:

Thank you for your reply to our letter of 23 July, 2004, concerning your Standpunt over medische beslissingen rond het levenseinde en euthanasie.

I am pleased to see that you do not mean to compel conscientious objectors to participate in euthanasia. This common point of departure promises a fruitful discussion of related issues.

The text of the statement from the Federatie Palliatieve Zorg Vlaanderen does clarify your understanding of the relationship between euthanasia and palliative care, but some points remain obscure.

On the one hand, the statement describes euthanasia as a legitimate part of the continuum of palliative care, so much so that a member of a palliative team might act as the second physician in processing a euthanasia request. On the other, the statement insists that a palliative care team member must not be expected to perform euthanasia. The rationale for this division of responsibilities is unclear. If euthanasia is a natural and morally legitimate extension of palliative care, upon what grounds do you insist that palliative care physicians must not directly participate in it?

Similarly, the Standpunt seems to emphasize the importance of multidisciplinary teamwork and the involvement of general practitioners, yet you state that you do not intend to make euthanasia part of the provision of normal health care. How can this separation be maintained if euthanasia is to be performed by medical personnel as part of a continuum of care, but not by specialists or euthanasia teams or clinics?

The formal statement appears to go further than your letter in its expectations of objecting physicians. The Standpunt asserts that an objecting physician must refer a patient to a physician willing to perform euthanasia, while your letter suggests that it would be sufficient to inform a patient of the existence of the helpline. I would like to be certain which of these assertions expresses the position of the signatories to the Standpunt.

The Standpunt includes, in English, references to "informed consent" and "shared decision making." ["Communicatie en overleg vormen de kern van het 'informed consent', de 'shared decision making' . . ."] The Project has found that these terms are now being used to override conscientious objections of physicians in order to serve the autonomy of the patient. Please advise what English language source was drawn upon in drafting this section of the document.

Finally, I would appreciate it if you would provide a copy of that part of your Patients' Rights Act that refers to a physician's obligations to provide a patient with information about "all possible

therapeutic options". You indicate that this obligation is accompanied by the right to fully express one's moral objections to a procedure, and I would like to see how the statute is phrased to strike this balance. The provision may suggest a means to resolve conflicts about the provision of information to patients.

Sincerely,

(Sean Murphy)
Administrator

Project Letter to the Belgian Association of General Practitioners
25 April, 2005
E-mailed Again on 6 October, 2004

Secretariaat, Nancy Denyn
Wetenschappelijke Vereniging van Vlaamse Huisartsen
St.-Hubertusstraat 58,
2600 Berchem,
Belgium

Dear Madam:

Upon reviewing Project correspondence, I note that I have not yet received a reply to our letter of 6 October, 2004 (attached).

I look forward to having a response in the near future.

Sincerely,

(Sean Murphy)
Administrator