

---

# **Euthanasia Policy and Practice in Belgium: Critical Observations and Suggestions for Improvement**

Raphael Cohen-Almagor, D.Phil.<sup>1</sup>

**ABSTRACT:** The essay opens with some background information about the context of euthanasia in Belgium. It proceeds by discussing the Belgian law on euthanasia and concerns about the law, its interpretations and implementation. Finally, the major developments and controversies since the law came into effect are discussed. Suggestions as to how to improve the Belgian law and circumscribe the practice of euthanasia are made, urging Belgian legislators and the medical establishment to reflect and study so as to prevent potential abuse of vulnerable patients.

---

This article investigates and discusses the practice of euthanasia in Belgium. Its methodology is based on critical review of the literature supplemented by interviews I conducted in Belgium with leading scholars and practitioners in February 2003 and February 2005. The interviews were conducted in English, usually in the interviewees' offices. The interviews were semi-structured. I began with a list of twenty-four questions (see Appendix), but did not insist on answers to all of them if I saw that the interviewee preferred to speak about subjects that were not included in the original questionnaire. The length of interviews varied from one to two and a half hours.

---

<sup>1</sup> Professor and Chair, University of Hull; author, *THE RIGHT TO DIE WITH DIGNITY: AN ARGUMENT IN ETHICS, MEDICINE AND LAW* (2001), *EUTHANASIA IN THE NETHERLANDS: THE POLICY AND PRACTICE OF MERCY KILLING* (2004); and *THE SCOPE OF TOLERANCE* (2006); editor, *MEDICAL ETHICS AT THE DAWN OF THE 21<sup>ST</sup> CENTURY* (2000); D.Phil., Oxford U., 1991. I thank J. Berre, Luc Deliens, Pierre-François Laterre, Freddy Mortier, Guido Van Steendam and Jean-Louis Vincent for their time and cooperation, to Wim Distelmans, Veerle Provoost, Jan Jans, Lawrence J. Schneiderman and the four referees of *Issues in Law and Medicine* for their constructive comments, and to Charles Sprung, Sigrid Sterckx and Etienne Vermeersch for their kind assistance. Unless said differently, all websites were last accessed on January 12, 2009. Keywords: euthanasia, Belgium, autonomy, dignity, National Evaluation and Control Commission for Euthanasia, palliative care.

After completing the first draft I sent the manuscript to my interviewees as well as to some leading experts for critical review and comments. The comments received were integrated into this final version of the essay. In 2008, while writing the final draft, I approached my interviewees and some other well-known experts and invited their comments and updates. Responses received by mid-January 2009 were integrated into the article.

This article provides background information about the context of euthanasia in Belgium. I then discuss the Belgian euthanasia law and concerns about the law, its practice and interpretations. Finally, I discuss the major developments and controversies since the law went into effect. Suggestions as to how to improve the Belgian law and practice of euthanasia are made, urging the Belgian legislators and medical establishment to reflect and study so as to prevent potential abuse. The Appendix contains my questionnaire.

### Background

Organized action in favor of the legislation of euthanasia started in Belgium in the 1980s with the foundation of the *Association belge pour le droit de mourir dans la dignité* (Belgian Association for the Right to Die with Dignity) (1981) and its Flemish counterpart *Vereniging voor het recht op waardig sterven* (Association for the Right to Die with Dignity) (1983). Some ten years later, the debate had reached parliament. During the parliamentary session 1995-1996 euthanasia bills were submitted to the senate by four members of parliament. Indeed, since 1995, legalization of euthanasia has been intensely debated by the media, scholars, the official Advisory Committee on Bioethics as well as by the Belgian Parliament. At that time, the Belgian *Comité consultatif de Bioéthique* (Consultative Committee on Bioethics) was founded to advise the federal and “community” governments and parliaments on bioethical issues. This Committee was composed of thirty-five members and thirty-five substitute members; among them medical doctors, nurses, magistrates, lawyers, social scientists, moral philosophers and theologians. The very first assignment, proposed by the presidents of the Chamber and the Senate, was to give advice concerning proposed euthanasia bills.<sup>2</sup>

Although the members disagreed on the fundamental questions, there was complete unanimity on the following topics: (a) The Dutch definition was adopted: “euthanasia is the intentional taking of someone’s life by another, on his request”; (b) It follows that this definition does not apply in the case of incompetent people; there the proposed terminology is “termination of life of incompetent people”; (c) More importantly, the act of stopping a pointless (futile) treatment is not euthanasia and it was recommended that the expression “passive euthanasia” not be used in these cases; and (d) What was sometimes called “indirect euthanasia,” increasing

---

<sup>2</sup> Etienne Vermeersch, “The Ethical and Historical Background of the Belgian and Dutch Laws on Euthanasia” (working paper).

the dosage of analgesics with a possible effect of shortening life, is also clearly distinguished from euthanasia proper.<sup>3</sup>

The Dutch experience was considered to be a good example to follow in Belgium. On November 28, 2000, the Dutch Lower House of parliament, by a vote of 104 to 40, approved the legalization of euthanasia. On April 10, 2001 the Dutch Upper House of parliament voted to legalize euthanasia, making the Netherlands the first and at that time only country in the world to legalize euthanasia. Forty-six members of the seventy-five seat Senate voted for the *Termination of Life on Request and Assistance with Suicide Act*; twenty-eight voted against; one member was not present. A year later, in April 2002, the law went into effect.<sup>4</sup>

Belgium debated whether to follow the euthanasia path of its Dutch neighbor. For some time, there were no formal registration and authorization procedures for end-of-life decisions in medical practice. Although euthanasia was illegal and treated as intentionally causing death under criminal law, prosecutions were unusual and, generally speaking, the practice of euthanasia was tolerated. Proposals to remove euthanasia from the criminal law had angered doctors who claimed they had not been properly consulted. Dr. Marc Moens, chairperson of the Belgian Association of Doctors Syndicates (BVAS), which comprised two thirds of the country's 40,000 doctors, argued that abolishing the law on euthanasia would do nothing to prevent abuses, but would make "the exception the rule."<sup>5</sup> Euthanasia is the exception. Caring for life should continue to be the rule.

Studies have shown that more than one in ten deaths among the country's ten million people is the result of "informal" euthanasia, where doctors gave patients drugs to hasten their deaths.<sup>6</sup> A study conducted in Flanders (the Dutch-Flemish speaking part of Belgium) in 1998 showed that despite lack of legislation permitting euthanasia, end-of-life decisions were common among general practitioners in Flanders, and that the frequency of deaths preceded by an end-of-life decision was similar to that in the Netherlands. In Flanders, where sixty percent of the population resides, more than five percent of all deaths in general practice (an estimated 1200 cases) resulted from the use of drugs with the explicit intention of shortening the patient's life.<sup>7</sup> The rate of administration of lethal drugs to patients without their explicit request was according to one research paper 3.2 percent<sup>8</sup> and according to

<sup>3</sup> *Id.*

<sup>4</sup> See [http://www.healthlaw.nl/wtlovhz\\_eng.pdf](http://www.healthlaw.nl/wtlovhz_eng.pdf); <http://www.nvve.nl/nvve2/pagina.asp?pagkey=72087>; <http://news.bbc.co.uk/1/hi/world/europe/1269682.stm>; <http://news.bbc.co.uk/1/hi/world/europe/1904789.stm>; and RAPHAEL COHEN-ALMAGOR, *EUTHANASIA IN THE NETHERLANDS*, *supra* note 1 at 37.

<sup>5</sup> Tony Sheldon, *Belgium Considers Legalizing Euthanasia*, 320 *BRIT. MED. J.* 137 (2000). See also PAUL SCHOTSMANS & TOM MEULENBERGS, *EUTHANASIA AND PALLIATIVE CARE IN THE LOW COUNTRIES* (2005).

<sup>6</sup> Andrew Osborn, *Belgians Follow Dutch by Legalising Euthanasia*, *THE GUARDIAN*, Oct. 26, 2001.

<sup>7</sup> Johan Bilsen et al., *The Incidence and Characteristics of End-of-Life Decisions by GPs in Belgium*, 21 *FAM. PRAC.* 282, 283, 286 (2004).

<sup>8</sup> Luc Deliens et al., *End-of-life Decisions in Medical Practice in Flanders, Belgium: A Nationwide Survey*, 356 *LANCET* 1806, 1806 (Nov. 25, 2000).

another published article, stemming from the same study, 3.8 percent, three times more frequent than euthanasia.<sup>9</sup> That is, more than three in 100 deaths in Belgium's northern Flemish region every year were the result of lethal injection without the patient's request.<sup>10</sup> Luc Deliens, medical sociologist and one of the authors of this study, said that countries that lack euthanasia law have more cases of ending life without patients' request than real euthanasia cases (on explicit request of the patient).<sup>11</sup> This is, of course, a contested argument that needs to be backed by concrete evidence that Deliens did not produce. At the same time, Deliens and colleagues wrote in an accompanying paper on the use of drugs for euthanasia that their study results indicated an inconsistent, poorly documented and substandard medical approach to euthanasia in Flanders.<sup>12</sup> Interestingly, among the twenty-five observed euthanasia cases in the study, three physicians reported an explicit request by the patient and, at the same time, the patient's incompetence.<sup>13</sup> Confusion among physicians was present in the end-of-life decision-making process. I will return to this disturbing phenomenon of ending patients' lives without their unequivocal request later on.

The Flanders study also showed that the incidence of euthanasia and physician-assisted suicide (PAS) was 1.5 percent.<sup>14</sup> In Belgium, unlike the Netherlands, the law only regulates euthanasia. It does not regulate PAS. In most cases euthanasia and PAS were discussed with relatives and non-staff members, and in just under half with other physicians or nurses.<sup>15</sup> The decision was not discussed with the patient in three out of four decisions at the end of life.<sup>16</sup> In general, the patient was perceived by the physician as competent. For all deaths preceded by an end-of-life decision, the time by which life was shortened was estimated by the physician as less than one day in just under a quarter of cases, with nearly 80 percent by less than a week. End-of-life decisions made without previous discussion with the patient or a previously stated wish were made in about two-thirds to three-quarters of all categories apart from euthanasia. The percentage of end-of-life decisions explicitly requested by close relatives varied. The patient's life was ended without request and by the

---

<sup>9</sup> Johan Bilsen et al., *supra* note 7, at 282, 284. The difference between the figures can be explained by the fact that the latter figure, 3.8 percent, relates only to general practitioners.

<sup>10</sup> Reuters, *Lethal Jabs Study Fuels Belgian Euthanasia Debate* (Nov. 24, 2000), at <http://worldrtd.net/news/world/?id=488> (accessed on July 21, 2007, no longer available).

<sup>11</sup> Interview with Prof. Luc Deliens, Department of Medical Sociology and Health Sciences, Free University of Brussels (Feb. 17, 2005). For further discussion, see EUTHANASIA IN INTERNATIONAL AND COMPARATIVE PERSPECTIVE (Marc Groenhuijsen & Floris van Laanen, eds., 2006); A. van der Heide, et al., *End-of-life Decision-making in Six European Countries: Descriptive Study*, 362 LANCET 345 (2003); JOHN GRIFFITHS, ET AL., EUTHANASIA AND LAW IN EUROPE (2008).

<sup>12</sup> R.H. Vander Stichele et al., *Drugs Used for Euthanasia in Flanders, Belgium*, 12 PHARMACOEPIDEMOLOGY & DRUG SAFETY 5 (2003).

<sup>13</sup> Luc Deliens et al., *supra* note 8, at "Discussion."

<sup>14</sup> Johan Bilsen et al., *supra* note 7, at 282.

<sup>15</sup> Luc Deliens et al., *supra* note 8, at Table 4.

<sup>16</sup> Johan Bilsen et al., *supra* note 7, at 282.

withdrawal or withholding of treatment mainly among incompetent patients.<sup>17</sup> A colleague was consulted in one in four end-of-life decisions.<sup>18</sup> Discussion with colleagues took place more often in these cases than for patients who received opioids with a potential life shortening effect.<sup>19</sup>

Between 1998 and 2001, there was a substantial decrease in the number of euthanasia cases. Luc Deliens argued that physicians became much more aware of needs of patients at the end of life, and the different possibilities that were opened for treatment, including palliative care. Deliens thought physicians and nurses were receiving better training; there was “improved attitude” towards patients; more equality in the relationships between physicians and patients; better communication between physicians and patients, making the patient as comfortable as is possible. He thought that decisionmaking at the end of life was becoming more ethical.<sup>20</sup>

Wim Distelmans is a cancer specialist and professor of palliative medicine at Brussels Free University. He is one of the pioneers in Belgium for the recognition of palliative care and fought for the right to euthanasia. Distelmans was president of the Federation Palliative Care Flanders and currently is President of the National Evaluation and Control Commission for Euthanasia. He contributed another point of view, that the number of euthanasia cases might be temporarily reduced because of the number of physicians that had been prosecuted for “murder” (Distelmans’ quotation marks). It was indeed thought by the press that the Public Prosecutor had become more active in view of the impending legalization of euthanasia. Distelmans was of the opinion that the increased number of registered euthanasia cases from 2002 on by the federal commission of euthanasia corroborated this opinion.<sup>21</sup>

### The Belgian Euthanasia Law

On January 20, 2001 the euthanasia commission of Belgium’s upper house, the Senate, voted in favor of proposed euthanasia legislation, which would exempt euthanasia from criminal prosecution, provided certain requirements are met.<sup>22</sup> Nine months later, on October 25, 2001, Belgium’s Senate approved the law proposal by a significant majority: 44 to 23, with two abstentions and two senators who failed to vote. It was clear beforehand that there was general support among all six parties in the ruling coalition of Socialists, Liberals and Ecologists.<sup>23</sup> In society at large, most people were behind the change. An opinion survey showed that three-quarters of

<sup>17</sup> Luc Deliens et al., *supra* note 8.

<sup>18</sup> Johan Bilsen et al., *supra* note 9, at 282. Compare A. van der Heide et al., *End-of-life Decision-making in Six European Countries: Descriptive Study*, 362 LANCET 345 (2003).

<sup>19</sup> Luc Deliens et al., *supra* note 8. See also F. Mortier et al., *End-of-life Decisions of Physicians in the City of Hasselt (Flanders, Belgium)*, 14 BIOETHICS 254 (2000).

<sup>20</sup> Interview with Prof. Luc Deliens, Brussels (Feb. 17, 2005).

<sup>21</sup> Wim Distelmans, personal communication (July 2, 2007).

<sup>22</sup> Wim Weber, *Belgian Euthanasia Bill Gains Momentum*, 357 LANCET 370 (2001).

<sup>23</sup> In both Belgium and the Netherlands, the euthanasia law was passed despite the objection of the Christian democrats.

those asked were broadly in favor of legalizing euthanasia.<sup>24</sup> On May 16, 2002, after two days of heated debate, the lower house of the Belgian parliament endorsed the bill by 86 votes in favor, 51 against, and ten abstentions.<sup>25</sup>

The legislation established the conditions under which doctors may end the lives of patients who are hopelessly ill and suffering unbearably. Potential candidates for euthanasia need to reside in Belgium to be granted this right. Patients must be at least 18 years old and make specific, voluntary and repeated requests that their lives be ended. The exact number of "repeated requests" is not specified and is open to interpretation. Section 3 of the law speaks of patients who are adults or emancipated minors, capable and conscious at the time of their request. "Emancipated minors" means an autonomous person capable of making decisions.<sup>26</sup> Freddy Mortier, professor of ethics and dean of the Faculty of Arts and Philosophy at Ghent University, explained that emancipated minors relate to "borderline cases of 16-17 year old patients."<sup>27</sup> Guido van Steendam, professor of ethics and director of the International Forum for Biophilosophy in Brussels, further explained that the legislators made the phrase vague on purpose, as a matter of principle, in order to defend the autonomy of younger patients.<sup>28</sup>

The patient's request must be made in writing. The document should be drawn up, dated and signed by the patient. If the patient's condition makes this infeasible, her request will be taken in writing by an adult of the patient's choice. That person must not benefit financially from the death of the patient. That person will specify that the patient is unable to express her request in writing and why. In such cases, the request will be written in the presence of the physician and the aforesaid person will name the physician in the document. This document must be included in the medical record. The patient may rescind the request at any time and in any manner, in which case the document is taken out of the medical record and returned to the patient. This provision was also granted under the Australian Northern Territory Act<sup>29</sup> and is granted under the Oregon *Death with Dignity Act*.<sup>30</sup>

Requests for euthanasia will be approved only if the patient is in a hopeless medical condition and complains of constant and *unbearable physical or mental pain* which cannot be relieved and is the result of a serious and incurable accidental or

---

<sup>24</sup> Andrew Osborn, *Belgians Follow Dutch by Legalising Euthanasia*, GUARDIAN, Oct. 26, 2001. Mortier said that several opinion polls indicated that 85-93% of the public supported the enactment of euthanasia law. Interview with Prof. Freddy Mortier, Dean of Faculty of Arts and Philosophy, Ghent University (Feb. 14, 2005).

<sup>25</sup> From the website of the Belgian Senate, [www.senate.be/home/legislation](http://www.senate.be/home/legislation), under the number 2-244/23 (last accessed July 21, 2007, no longer available).

<sup>26</sup> Interview with Prof. Pierre-François Laterre, Director, Intensive Care Unit, St. Luc Hospital, Brussels (Feb. 5, 2003).

<sup>27</sup> Interview with Prof. Freddy Mortier, Ghent (Feb. 6, 2003).

<sup>28</sup> Interview with Prof. Guido Van Steendam, Director, Biophilosophy Center, STARLAB, Brussels (Feb. 5, 2003).

<sup>29</sup> Andrew L. Plattner, *Australia's Northern Territory: The First Jurisdiction to Legislate Voluntary Euthanasia, and the First to Repeal It*, 1 DEPAUL J. HEALTH CARE L. 648 (1997).

<sup>30</sup> 13 Or. Rev. Stat. § 3.07 (1998).

pathological condition. At least one month must elapse between the written request and the mercy killing.<sup>31</sup> The one-month requirement is valid only when the patient is not considered “terminally ill” (e.g., neurological conditions like quadriplegia).

The one month requirement is a tricky issue especially for patients and doctors in intensive care units. Professor Jean-Louis Vincent, Head of the Department of Intensive Care in Erasme Hospital (University of Brussels), says that he and his staff do not wait for one month as the law requires: “The law is not applicable to ICU.”<sup>32</sup> The average stay in his department is 3.5 days, and treatment depends on the condition. According to Vincent, when doctors see that there is no help available, they put patients to sleep. Beneficence is the guiding rule.

The patient’s physician must inform the patient of the state of her health and of life expectancy, discuss with the patient her request for euthanasia and the therapeutic measures which can still be considered, as well as the availability and consequences of palliative care.<sup>33</sup> This provision is crucial, as sometimes the patient’s decision may be influenced by severe pain.<sup>34</sup>

Freddy Mortier explained that for some time palliative care was viewed with disfavor as palliation seemed contrary to euthanasia. People who supported the euthanasia law thought the option of palliative care was somehow contradictory to the practice of euthanasia. Many adversaries of euthanasia thought that providing palliative care might eliminate euthanasia all together. During the debate before the legalization in 2000–2001, people primarily from the Catholic universities argued that euthanasia would disappear once palliative care is provided. So including the requirement to consult an expert in palliative care was rejected in parliament. However, together with the euthanasia bill another bill was passed for organized palliative care.<sup>35</sup> This bill provided the basis for a steep increase in the means that were already available for palliative care. Still, as Jan Jans remarked, while the bill on palliative care was clear on the need for substantial additional training and updating, the euthanasia bill did not translate this need into requirements with regard to the palliative competence of the physician involved.<sup>36</sup>

Mortier maintained that the situation has changed for the better since 2000–2001. There is dialogue between proponents of euthanasia and proponents of pal-

---

<sup>31</sup> Belgian Euthanasia Law, Ch. 2, Sec. 3, available at <http://www.kuleuven.ac.be/cbmer/viewpic.php?LAN=E&TABLE=DOCS&ID=23>.

<sup>32</sup> Interview with Prof. J. L. Vincent and Dr. J. Berre, Erasme Hospital, Brussels (Feb. 6, 2003).

<sup>33</sup> Belgian Euthanasia Law, *supra* note 31, at Sec. 3.

<sup>34</sup> On the different conceptions of pain that physicians and patients have, see William Ruddick, *Do Doctors Undertreat Pain?* 11 *BIOETHICS* 246 (1997). It is argued that adequate pain control is often neglected for nursing home residents, and that nursing home staff underestimate the true pain burden experienced by residents. See Joan M. Teno et al., *Persistent Pain in Nursing Home Residents*, 285 *JAMA* 2081 (Apr. 25, 2001). See also the Nov. 12, 2003, edition of *JAMA*, which was dedicated to discussing pain and pain management.

<sup>35</sup> Interview with Prof. Freddy Mortier, Ghent (Feb. 14, 2005).

<sup>36</sup> Jan Jans, *The Belgian “Act on Euthanasia”: Clarifying Context, Legislation, and Practice from an Ethical Point of View*, 25 *J. SOC’Y CHRISTIAN ETHICS* 171 (2005). For comparative analysis, see R. Cohen-Almagor, *Dutch Perspectives on Palliative Care in the Netherlands*, 18 *ISSUES IN LAW & MED.* 111 (2002).

liative care. The mood is more favorable to include palliative care in the process. Mortier noted that in 40 percent of the reported cases concerning terminal patients, palliative care specialists were consulted. In non-terminal patients, 20 percent included consultation with palliative care specialists. Palliative care physicians are involved in the process.<sup>37</sup> On the other hand, Hubert van Humbeeck noted in his remarks on a draft of this article that palliative care was growing in importance, but as the political urgency evaporated, politicians were no longer interested in providing more money. Palliative care is expensive and, therefore, palliative care units are struggling. Some are shutting down.<sup>38</sup>

In this context, Ganzini and colleagues reported that as a result of palliative care, some patients in Oregon changed their minds about assisted suicide.<sup>39</sup> The World Health Organization defines palliative care as the “active, total care of patients whose disease is not responsive to curative treatment,” maintaining that control of pain, of other symptoms, and of psychological, social, and spiritual problems, is paramount.<sup>40</sup> The medical staff must examine whether it is possible to prevent or to ease the pain by means of medication and palliative care.<sup>41</sup> Like the Belgian law, the Oregon Death with Dignity Act requires the attending physician to inform the patient of all feasible alternatives, including comfort care, hospice care and pain control.<sup>42</sup>

According to Belgian law, the physician must have reached, with the patient, the conviction that there is no other reasonable solution to the situation and that the patient’s request is entirely voluntary. The physician is also required to ascertain the

---

<sup>37</sup> Interview with Mortier (Feb. 14, 2005). See also Luc Deliens & Jan Bernheim, *Palliative Care and Euthanasia in Countries with a Law on Euthanasia*, 17 *PALLIATIVE MED.* 393 (2003).

<sup>38</sup> Personal communication (June 27, 2007). For further discussion, see JOHN GRIFFITHS ET AL., *EUTHANASIA AND LAW IN EUROPE* 269 (2008). One referee objected to this assertion, writing that palliative care is not expensive and that there is a body of literature that shows that palliative care saves hospitals money. The services themselves do not make money, and are usually neutral-financially. However, they save hospitals money when a patient decides to forego expensive interventions and opt for comfort care.

<sup>39</sup> Linda Ganzini et al., *Physicians’ Experiences with the Oregon Death with Dignity Act*, 342 *NEW ENG. J. MED.* 563 (2000).

<sup>40</sup> WORLD HEALTH ORGANIZATION, *CANCER PAIN RELIEF AND PALLIATIVE CARE: REPORT OF A WHO EXPERT COMMITTEE* 11 (1990).

<sup>41</sup> For further deliberation on pain control mechanisms and their importance, see Timothy E. Quill et al., *Palliative Options of Last Resort*, 278 *JAMA* 2099 (Dec. 17, 1997); *TEXTBOOK OF PALLIATIVE MEDICINE* (P. D. Doyle et al., eds., 1998); Timothy E. Quill et al., *Palliative Treatments of Last Resort: Choosing the Least Harmful Alternative*, 132 *ANNALS INTERNAL MED.* 488 (Mar. 21, 2000); S. Bauwens et al., *Attitudes and Knowledge about Cancer Pain in Flanders: The Educational Effect of Workshops Regarding Pain and Symptom Control*, 15 *PALLIATIVE MED.* 181 (2001); *ETHICAL ISSUES IN CHRONIC PAIN MANAGEMENT* (Michael E. Schatman, ed., 2007). For further discussion on making palliative care decisions for incompetent patients, see Jason H.T. Karlawish et al., *A Consensus-Based Approach to Providing Palliative Care to Patients Who Lack Decision-Making Capacity*, 130 *ANNALS INTERNAL MED.* 835 (May 18, 1999).

<sup>42</sup> 13 Or. Rev. Stat. § 3.01 (1998). For a comparative study of palliative care laws in Australia, Canada, the United Kingdom, Poland, France, the Netherlands, Germany and Japan, see Danuta Mendelson & Timothy Stoltzfus Jost, *A Comparative Study of the Law of Palliative Care and End-of-Life Treatment*, 31 *J. L. MED. & ETHICS* 130 (2003).



persistent nature of the patient's physical or mental pain and of her reiterated wish. To this end, the physician is required to conduct several interviews with the patient, reasonably spaced, with due regard to the evolution of the patient's condition.<sup>43</sup>

All cases of mercy killing have to be fully documented in a special format and presented to a permanent monitoring committee, the National Evaluation and Control Commission for Euthanasia, established by the government in September 2002. If a case is not approved by at least two-thirds of the Commission members, it must be referred to the state prosecutor for further investigation.<sup>44</sup>

The Commission is composed of sixteen members who are selected because of their knowledge and experience in the matters relevant to the mandate of the Commission. Eight of those members are physicians, of whom at least four are professors in a Belgian university. Four members are either law professors in a Belgian university, or lawyers. Four members are selected from facilities entrusted with the problems of patients suffering from an incurable disease. Members of one of the houses of parliament, of the federal government, of a governmental body of a community, or of a region cannot serve on the Commission. The members of the Commission are appointed for a term of four years by royal decree after deliberation by the council of ministers. The appointments include consideration of linguistic parity. Each linguistic group will be composed of at least three candidates of each sex and must reflect a pluralist political representation. The Commission is presided over by one French-speaking and one Dutch-speaking president. The presidents are elected by the members of the Commission who belong to their respective linguistic group.<sup>45</sup> The Belgians are sensitive to the cultural differences between Flemish and Walloons.

The Commission reviews the registered and duly completed document received from the physician. The Commission ascertains whether euthanasia was performed in compliance with the conditions and procedures required by law. When in doubt, the Commission may, by a majority vote, decide to waive the anonymity of the document. The Commission may request from the treating physician all the contents of the medical record which pertain to the euthanasia. The Commission is required to render a decision within two months.<sup>46</sup>

Thus, Belgium developed its own model of assessment. While in the Netherlands there are five regional committees, in Belgium there is one commission. In the Netherlands, the names of the reviewed physicians are known to the regional committees. Members of the committees are able to summon doctors for inquiries if they feel that something in the decision-making process was flawed. In Belgium, the

---

<sup>43</sup> Belgian Euthanasia Law, *supra* note 31, at Sec. 3.

<sup>44</sup> *Rationalist International*, Bull. 104, Oct. 27, 2002, available at <http://www.rationalistinternational.net/>. See also W. Distelmans, *De Federale Controle—en Evaluatiecommissie inzake de toepassing van de wet van 28 mei 2002 betreffende de euthanasie* (Federal Committee for Surveillance and Evaluation of Legalizing Euthanasia on May 28, 2002), 60 *TIJDSCHRIFT VOOR GENEESKUNDE* (Belgian J. Med.) 232 (2004).

<sup>45</sup> Belgian Euthanasia Law, *supra* note 31, at Ch. 5, Sec. 6.

<sup>46</sup> *Id.* at Sec. 8.

names of the physicians remain anonymous. As a general rule, the Commission sees only the public part of the physicians' reports. Only when there are doubts about compliance may the commission vote whether it should also see the confidential parts. Deliens thinks the Dutch system is better because there is more feedback between the regional committees and physicians. In Belgium, the Commission has more limited information.<sup>47</sup>

Section 14 of the euthanasia law thoughtfully includes a conscience clause that no physician is required to perform euthanasia, and that no one is required to otherwise participate in euthanasia. Indeed, doctors must not be coerced into taking actions that contradict their conscience or their understanding of their role. This provision was also provided under the Australian Northern Territory Act.<sup>48</sup>

If the physician who receives a request refuses to perform euthanasia, he must, within a reasonable time, inform the patient or her representative, and specify his reasons. In case his refusal is based on a medical consideration, this consideration must be entered into the patient's medical record. The physician who refuses to act upon a request for euthanasia must, at the request of the patient or the patient's representative, transfer the patient's medical record to the physician designated by the patient or by her representative.<sup>49</sup>

### Concerns About the Law

Belgian doctors voiced opposition to the new law because it opened the door for ending life too wide. Unlike the Dutch doctors, no medical association in Belgium supported euthanasia. Doctors from the Belgian Medical Association said they were concerned that the law will permit ending life in cases where a patient has an incurable disease but still has years to live. Marc Moens said, "Doctors know that this law is simply flawed and find it totally unacceptable that individuals who are not terminally ill will also be eligible for euthanasia."<sup>50</sup> Unlike the Netherlands, in Belgium a second doctor may also be consulted in cases where the patient is unlikely to die naturally within a short period of time. That is, an end-of-life procedure also exists for non-terminally ill patients.

In 2003, Pierre-François Laterre, Director of the Intensive Care Unit at St. Luc Hospital, said that the law was inadequate to protect patient rights because there

<sup>47</sup> Interview with Prof. Luc Deliens, Department of Medical Sociology and Health Sciences, Free University of Brussels (Feb. 17, 2005). For comparative analysis of the euthanasia laws in Belgium and the Netherlands, see Jan Jans, *The Belgian "Act on Euthanasia": Clarifying Context, Legislation, and Practice from an Ethical Point of View*, 25 J. SOCIETY CHRISTIAN ETHICS 165 (2005).

<sup>48</sup> Andrew L. Plattner, *supra* note 29. The Illinois proposed bill to legislate PAS included a "Provider's Freedom of Conscience" clause, which explicitly said that physicians who object to the practice may not be required to participate or aid in physician-assisted suicide (PAS). Cf. Russell Korobkin, *Physician-Assisted Suicide Legislation: Issues and Preliminary Responses*, 12 NOTRE DAME J. L., ETHICS & PUB. POL'Y 464 (1998).

<sup>49</sup> Belgian Euthanasia Law, *supra* note 31, at Ch. 6, Sec. 14.

<sup>50</sup> Justin Sparks, *Belgian Docs Unhappy About Proposed Euthanasia Law*, REUTERS HEALTH, May 16, 2002. See also Herman Nys, *Euthanasia in the Low Countries: A Comparative Analysis of the Law Regarding Euthanasia in Belgium and the Netherlands*, ETHICAL PERSPECTIVES, June 2002, at 73.

were not enough safeguards. He thought the focus should be on adequate palliative care. In his opinion, if palliative care was organized carefully, there would be no need for euthanasia.<sup>51</sup> Two years later, Laterre's view of the law was more favorable. He said that the law reflected the common denominator of opinion. Laterre and Deliens thought that the law was neither too broad, nor too narrow. The law did not change the practice as far as Laterre, an intensive care (IC) specialist, was concerned. Laterre testified that he did not need regulation to decide when to end life. He was in favor of withholding or withdrawing care when quality of life was very poor. Here Laterre's view was similar to that expressed by Jean-Louis Vincent, another prominent IC specialist, who maintained that the law did not help very much because it dealt with a very limited number of patients.<sup>52</sup>

Luc Deliens regarded the law as an important constitutional tool as it had lifted a taboo. To his mind, while physicians in most other countries do not speak of end-of-life decisions openly, "in Belgium we speak openly about terminating the life of dying competent patients." In other countries, physicians probably have the same euthanasia practice, but it is done secretly. In Belgium, "we believe it is better to discuss things in order to have an exchange of ideas and expertise."<sup>53</sup> These statements echo opinions I heard from Dutch experts explaining the advantages of the euthanasia law in the Netherlands.<sup>54</sup>

Veerle Provoost also expresses a favorable opinion of the law. She sees it as "a starting point." Besides the fact that it creates better clarity about the situation and provides more security for physicians who help their patients, it also has a number of other positive effects. Among them, she says, there is more debate about the topic in general and there are a number of initiatives proposed by groups of professionals to inform physicians and health workers, such as LEIF (end of life information forum), a group that provides information about the best way to respond when patients request euthanasia, where to find support, and information about palliative care organizations.<sup>55</sup>

In 2009, Provoost thinks the law, generally speaking, is working well. However, she points out that there are a few things that need to be addressed. First, two important groups of patients are not helped by this law: (1) underage people, which may be a form of discrimination in her view; and (2) people who have dementia (e.g., Alzheimers). Second, another aspect that would need to change, argues Provoost (also according to Wim Distelmans), is that physicians are not obligated to refer patients to another physician when they decide not to honor the patient's request.

---

<sup>51</sup> Interview with Prof. Pierre-François Laterre, Brussels (Feb. 5, 2003).

<sup>52</sup> Interview with Prof. Jean-Louis Vincent and Dr. J. Berre, Erasme Hospital, Brussels (Feb. 6, 2003).

<sup>53</sup> Interview with Prof. Luc Deliens, Department of Medical Sociology and Health Sciences, Free University of Brussels (Feb. 17, 2005).

<sup>54</sup> R. COHEN-ALMAGOR, EUTHANASIA IN THE NETHERLANDS, *supra* note 1.

<sup>55</sup> Personal communication on Jan. 16, 2009.

Third, it remains unclear how institutions (mostly nursing homes and hospitals) deal with requests from their patients. Provoost writes: "People I know who work in healthcare or bioethics and deal with institutions tell me that a number of those say that their patients can get euthanasia when their request is in line with the stipulations in the law; however, in practice most of these requests, even when they are in line with the law, are ignored. This is a problem especially considering the fact that physicians are not obliged to refer the patient to another physician. Certainly for elderly patients who are socially isolated this is a very problematic situation" as most of them "cannot arrange a visit to another physician themselves."<sup>56</sup>

Freddy Mortier provided a similar opinion. He thought that the law was too narrow as it relates to adults and he would have liked to expand the law to 16 year-old patients and above. Although the law does mention "emancipated minors," Mortier argued that in borderline cases of 16 to 17 year old patients there were very few cases of emancipated minors who received physician-assisted suicide. Mortier felt that young people may be mature enough to weigh the burdens and benefits of the proposed treatment and can decide for themselves whether they should accept treatment. Furthermore, Mortier also favored including PAS in the law.<sup>57</sup> Conversely, Guido van Steendam thought that the law was over broad, even broader than in the Netherlands. For instance, a mental condition that causes a patient to wish to die is accepted as grounds for euthanasia. Section 3 speaks of a patient who is in a hopeless medical condition and complains of constant and unbearable physical or mental pain that cannot be relieved and is the result of a serious and incurable accidental or pathological condition.<sup>58</sup> Van Steendam also maintained that the law increased public attention and awareness of euthanasia.<sup>59</sup>

Thus, the law opens the door for physically healthy persons to request that their lives be ended because they are tired of life. Does a person who finds no meaning in life suffer unbearably? It would be very difficult, almost impossible, for an assessment committee to judge whether the criteria for euthanasia are satisfied, if the symptoms cannot be interpreted in the context of the physical condition. Instead, such patients should be provided medical care and psychiatric treatment in order to alleviate the depression, not euthanasia.<sup>60</sup> In the Netherlands, there was a case of a patient named Edward Brongersma, an 86-year-old man, who requested euthanasia from his general practitioner (GP), Dr. Philip Sutorius, on grounds that death had "forgotten" him, his friends and relatives were dead, and he experienced

---

<sup>56</sup> Personal communication on Jan. 16, 2009.

<sup>57</sup> Interviews with Prof. Freddy Mortier, Ghent (Feb. 6, 2003; Feb. 14, 2005).

<sup>58</sup> Belgian Euthanasia Law, *supra* note 31, at Sec. 3.

<sup>59</sup> Interview with Prof. Guido van Steendam, Brussels (Feb. 5, 2003).

<sup>60</sup> A recent study argues that the current practice of physician-assisted suicide as permitted by the Oregon Death with Dignity Act may fail to protect some patients whose choices are influenced by depression. Linda Ganzini et al., *Prevalence of Depression and Anxiety in Patients Requesting Physicians' Aid in Dying: Cross Sectional Survey*, 337 BRIT. MED. J. 1682 (2008).

“a pointless and empty existence.”<sup>61</sup> After repeated requests, Sutorius provided assistance in suicide. The public prosecutor requested that Sutorius be given a three month suspended prison sentence. The prosecution recognized that the requirement in Dutch law (that also appears in the Belgian law) for “hopeless and unbearable suffering” was not met. Therefore, the patient’s request should have been refused.<sup>62</sup>

The trial court acquitted Sutorius in November, 2000, but the Amsterdam appellate court found him guilty of assisted suicide, claiming that Brongersma’s suffering was not medical and that Sutorius therefore was unqualified to judge such an issue. The court believed Sutorius had promised to fulfill Brongersma’s request to die too soon, instead of seeking other solutions. However, the court imposed no punishment, recognizing that Sutorius had acted out of concern for his patient.<sup>63</sup>

Dr. Sutorius appealed to the Supreme Court in order to quash his conviction and clarify the position of doctors. The Supreme Court held that the euthanasia law specifically did not include such “tired of life situations.” Its decision underlines the earlier judgment that “unbearable and hopeless suffering,” a criterion laid down in the law on euthanasia, must be linked to a recognizable medical or psychiatric condition. Legal experts consulted by the appellate court had concluded that there was no legal framework for doctors to act other than over demonstrable medical suffering.<sup>64</sup>

The Royal Dutch Medical Association commented by saying that the definition of “unbearable suffering” had been stretched too far and that “what is new is that it goes beyond physical or psychiatric illness to include social decline.” The Dutch Justice Minister Benk Korthals had said that being “tired of life” is not sufficient reason for euthanasia.<sup>65</sup>

Belgian law necessitates a long-term relationship between the doctor practicing euthanasia and the patient. I mentioned that potential candidates for euthanasia are required to reside in Belgium. In a case of a nursing team that has regular contact with the patient, the general practitioner must discuss the patient’s request with that team or with members of that team. If the patient requests it, the GP must also discuss the patient’s request with the proxies appointed by the patient. Controversially, there is also a provision for patients who are not in the final phases of a terminal illness to

---

<sup>61</sup> Tony Sheldon, *Dutch GP Cleared After Helping to End Man’s “Hopeless Existence”*, 321 BRIT. MED. J. 1174 (2000).

<sup>62</sup> *Id.*

<sup>63</sup> Tony Sheldon, *Doctor Convicted of Helping Patient to Commit Suicide May Be Retried*, 325 BRIT. MED. J. 924 (2002); Tony Sheldon, “Existential” Suffering Not a Justification for Euthanasia, 323 BRIT. MED. J. 1384 (2001); *Dutch Doctor Is Convicted In Suicide Case*, N.Y. TIMES, Dec. 9, 2001.

<sup>64</sup> Tony Sheldon, *Being “Tired of Life” Is Not Grounds for Euthanasia*, 326 BRIT. MED. J. 71 (Jan. 11, 2003).

<sup>65</sup> *Id.*; Tony Sheldon, *supra* note 61. While I am very critical of the case, others perceive the GP’s conduct as a “logical extension” of pro-voluntary euthanasia reasoning as it accords with respect for autonomy and beneficence. See Richard Huxtable & Maaïke Moller, “Setting a Principled Boundary”? Euthanasia as a Response to “Life Fatigue”, 21 BIOETHICS 117 (2007).

opt for euthanasia. Such a request requires a further authorization by a psychiatrist or a specialist in the disease. The consultant must be independent with regard to the patient, her GP, and also with regard to the first consultant.<sup>66</sup>

### Concerns About End-of-Life Practices

A major concern relates to the number of people who are killed without their request. In 1998, Deliens and colleagues estimated that 705 patients (1.3 percent of all deaths) died from voluntary euthanasia or PAS, and that in 1796 cases (3.3 percent of all deaths) lethal drugs were administered without the patient's explicit request.<sup>67</sup> Thus, ending life without request was more common than euthanasia. In 2001, 1.5 percent of all deaths involved ending life without the patient's request. Thus, fear of abuse is certainly relevant. One way to address this issue is to promote physician-assisted suicide instead of euthanasia for all patients requesting assistance and who are able to swallow the lethal dose.<sup>68</sup> In Belgium, however, doctors like to have full control over their actions. Administration of lethal drugs means taking responsibility. Consequently, PAS is not included in the law. I suggest having a full and open public discussion of this issue, allowing all parties to air different opinions, and provide public forums, which people in Belgium like and appreciate. Topics should include research findings, the fear of abuse, and PAS as an alternative to euthanasia.

A related concern is the practice of terminal sedation. It is not euthanasia, or as some people in Belgium and the Netherlands term "slow euthanasia,"<sup>69</sup> because euthanasia requires the consent of the patient, while terminal sedation does not. Here the fear of abuse is great. Provoost argued that in some institutions and for a number of physicians, it is an alternative for euthanasia.<sup>70</sup> Laterre said that terminal sedation happened frequently in intensive care units (ICUs). He saw the practice as the middle approach between euthanasia and withholding treatment.<sup>71</sup> According to Vincent, terminal sedation was the most common death in the ICU, accounting for one-half of all hospital deaths.<sup>72</sup> Mortier estimated that eight percent of all deaths in 2001 were cases of terminal sedation, accounting for about 4,500 cases in Flanders

---

<sup>66</sup> Belgian Euthanasia Law, *supra* note 31, at Ch. II (Procedure and Conditions), art. 3, § 3.

<sup>67</sup> Luc Deliens et al., *supra* note 8.

<sup>68</sup> Lawrence Schneiderman prefers the more neutral term physician aid in dying (PAD). I prefer the more precise term physician-assisted suicide (PAS).

<sup>69</sup> Interview with Prof. Freddy Mortier, Dean of Faculty of Arts and Philosophy, Ghent University (Feb. 14, 2005); "Slow Euthanasia" is the Way to Go, *Say Dutch Doctors*, BIOEDGE, no. 122, June 4, 2004, available at <http://www.australasianbioethics.org/Newsletters/122-2004-06-04.html#slow>; European Association for Palliative Care, *Sedation is Not "Slow Euthanasia,"* available at <http://www.eapcnet.org/forum/default.asp?comment=172>. See also Charles Douglas et al., *Managing Intentions: The End-of-Life Administration of Analgesics and Sedatives, and Possibility of "Slow Euthanasia,"* 22 *BIOETHICS* 388 (2008).

<sup>70</sup> Personal communication on Jan. 16, 2009.

<sup>71</sup> Interview with Prof. Pierre-François Laterre, Brussels (Feb. 16, 2005).

<sup>72</sup> Personal communication of Jean-Louis Vincent (Dec. 10, 2008).

alone.<sup>73</sup> There is no knowledge of whether the patient's consent was sought or given. At present the Belgian physicians do not have any law or medical guidelines on this. There is no legal regulation and no public or professional scrutiny to examine to what extent the procedure has adequate safeguards, and there is no knowledge of whether consultation was provided.<sup>74</sup> This situation calls for a change. There should be clear guidelines as to when it is appropriate, if at all, to resort to this practice.

Section 3 of the law holds that the euthanasia request should be voluntary, well thought out and reiterated, and should not be the result of outside pressure.<sup>75</sup> Indeed, it must be ensured that the patient's decision is not a result of familial and environmental pressures. At times, patients may feel that they constitute a burden on their loved ones. It is the task of social workers to examine patients' motives and to see to what extent they are affected by various external pressures (as opposed to a truly free will to die). The law should specify the mechanism for ensuring that the request is voluntary.

One issue that is not addressed at all in the law is whether physicians may suggest euthanasia to their patients. Presently euthanasia may be suggested by doctors.<sup>76</sup> In the Netherlands, a report of Dutch Medical Association on euthanasia describes a situation in which the physician has the impression that the patient would like to start a conversation about the end of his life and his wishes concerning the end of his life, but hesitates to start this conversation. If this is the case, then the physician may choose to open this conversation. However, the medical association instructs physicians that this must be done with the utmost caution. Caution is needed in order to avoid making the patient feel pressured to consider euthanasia.<sup>77</sup> The first Dutch comprehensive study on end-of-life decisions shows that 36 percent of specialists, 24 percent of home physicians, and 65 percent of general practitioners believed that there may be situations in which the physician should raise euthanasia as a possibility with the patient.<sup>78</sup> The 1990 prospective study shows that the initiative for discussion about the action to be performed at the end of life came from the patient in only about half of the cases.<sup>79</sup> Van der Maas and Van der Wal estimated that of all the cases of euthanasia, physician-assisted

---

<sup>73</sup> Johan Bilsen et al., *Changes in Medical End-of-Life Practices During the Legalization Process of Euthanasia in Belgium*, 65 *SOC. SCI. & MED.* 803 (2007).

<sup>74</sup> Interview with Prof. Freddy Mortier, Dean of Faculty of Arts and Philosophy, Ghent University (Feb. 14, 2005).

<sup>75</sup> Belgian Euthanasia Law, *supra* note 31, at Sec. 3.

<sup>76</sup> Interview with Prof. Guido Van Steendam, Brussels (Feb. 5, 2003).

<sup>77</sup> INZAKE EUTHANASIE: KONINKLIJKE NEDERLANDSCHE MAATSCHAPPIJ TOT BEVORDERING DER GENEESKUNST (Concerning Euthanasia: The Royal Dutch Society of Medicine) 15 (1995) (ISBN 90-71994-10-4). See also *Discussienota van de Werkgroep Euthanasie, van de Koninklijke Maatschappij tot Bevordering der Geneeskunst (KNMG)* (Discussion Paper of the Task Force on Euthanasia of the Royal Dutch Society of Medicine), *MEDISCH CONTACT*, vol. 30, 1975, at 7.

<sup>78</sup> P.J. VAN DER MAAS ET AL., *EUTHANASIA AND OTHER MEDICAL DECISIONS CONCERNING THE END OF LIFE*, *HEALTH POLICY MONOGRAPHS* 102 (1992).

<sup>79</sup> *Id.* at 156.

suicide, and ending of life without the patient's explicit request, the physician initiated the discussion in 21 percent of cases.<sup>80</sup> Another study showed that 54 percent of physicians believed that in certain situations it was the physician's professional duty to suggest euthanasia as an option to the patient.<sup>81</sup>

Indeed, this was one of my concerns when I did my independent study in the Netherlands.<sup>82</sup> Neither the physicians nor the study's investigators addressed the extent to which the voluntariness of the process may be compromised by suggesting the option of euthanasia to the patient.<sup>83</sup> A 1998 study in the city of Hasselt, Flanders, had shown that physicians' attitudes toward euthanasia are clearly related to end-of-life decisions, and that physicians who oppose euthanasia refrain from using lethal drugs whereas physicians who are approving of euthanasia may resort to the practice.<sup>84</sup> Evidently physicians have great influence over their patients.

The physician's role is commonly understood as a healing role.<sup>85</sup> With respect to professional ethics, talking about euthanasia upon a patient's request is different from suggesting it to the patient. When a physician talks about the option of euthanasia upon the patient's request, we are faced with the exceptional situation in which patient's autonomy and the physician's understanding of beneficence meet and manifest in the option of euthanasia. Thus, in this particular case, the healing model may be compromised in order to allow medical intervention based on a consensus between the patient and the physician in accordance with the principles of beneficence and patient autonomy. But when euthanasia is accentuated, the emphasis on euthanasia might undermine the patient's voluntary wishes.

Thus it is argued that physicians' suggestions constitute a powerful influence on the patients' choices of treatment. The patients' choices may reflect their physicians' attitude. The patient, who trusts the long-time GP, might feel that he is being condemned to death and that he is wasting the doctor's time. When all is said and done, all the physician has to offer him is death. Putting emphasis on euthanasia by the physician might undermine the will to live and to explore further avenues for treatment. Therefore any reluctance shown by patients in regard to this issue should be honoured and respected.<sup>86</sup>

---

<sup>80</sup> Paul J. van der Maas & Gerrit van der Wal, *Letter to the Editor*, 336 NEW ENG. J. MED. 1386 (1997).

<sup>81</sup> Paul van der Maas & Linda L. Emanuel, *Factual Findings*, in REGULATING HOW WE DIE 168 (L.L. Emanuel, ed., 1998).

<sup>82</sup> R. COHEN-ALMAGOR, EUTHANASIA IN THE NETHERLANDS, *supra* note 1. See also Raphael Cohen-Almagor, *An Outsider's View on the Dutch Euthanasia Policy and Practice*, 17 ISSUES IN LAW & MED. 35 (2001).

<sup>83</sup> Herbert Hendin et al., *Physician-Assisted Suicide and Euthanasia in the Netherlands*, 277 JAMA 1721 (1997).

<sup>84</sup> F. Mortier et al., *Attitudes, Sociodemographic Characteristics, and Actual End-of-Life Decisions of Physicians in Flanders, Belgium*, 23 MED. DECISION MAKING 502 (2003).

<sup>85</sup> See J.R. Peteet, *Treating Patients Who Request Assisted Suicide: A Closer Look at the Physician's Role*, 3 ARCH. FAM MED. 723 (1994); E. Rosenthal, *When a Physician Is Asked, "Help Me Die,"* N.Y. TIMES, Mar. 13, 1997, at A1, B4; Fiona Godlee, *The Role of the Doctor*, 335 BRIT. MED. J. (Nov. 17, 2007), available at <http://www.bmj.com/cgi/content/full/335/7628/0>.

<sup>86</sup> R. COHEN-ALMAGOR, THE RIGHT TO DIE WITH DIGNITY, *supra* note 1.



The role of the physician is not to push patients to choose euthanasia. Today, in Belgium, it is difficult to argue that patients are unaware of the option.<sup>87</sup> As euthanasia has been debated for many years in different circles of society and over the mass media, it can be assumed that ignorance is hardly a prominent factor. The voluntary nature of the request must be established before considering it. Hence, physicians need to ask themselves why patients are reluctant to raise the issue. They must examine all relevant and possible answers, including the possibility that the patient wishes to live despite her severe illness and medical condition. The physician should consider the consequences of the way they frame the discussion of the patient's condition on the patient's loved ones, and on the doctor-patient relationship built on trust over the years. In a matter of life and death, caution is not only recommended, it is a must.

An independent physician must be consulted regarding the serious and incurable nature of the condition. The consulting doctor is required to inspect the medical file, to examine the patient, and must ascertain the enduring and unbearable physical or mental suffering. The physician is then required to write a report.<sup>88</sup> My study of euthanasia in the Netherlands showed that sometimes the consultation was conducted over the phone.<sup>89</sup> I wondered whether this might be the case also in Belgium. Mortier said that consulting over the phone was impossible. The consultant needs to see the patient.<sup>90</sup> I asked him the same question in 2005 and Mortier still knew of no cases of consultation by phone.<sup>91</sup> Van Steendam, on the other hand, said that in practice there were cases of consultation over the phone. The consultant should see the patient. It is required by law, but sometimes this was not the case.<sup>92</sup>

Another concern arising from my study of euthanasia in the Netherlands has to do with the identity of the consultant. Section 3 of the Belgian law merely states that the physician needs to obtain a consultation with a second physician, either a psychiatrist or a specialist of the patient's pathology, specifying the reasons for the consultation.<sup>93</sup> I began to worry about this issue after watching the Dutch movie *Death on Request*. In this historic movie, the very first that documented a doctor administering lethal drugs to kill a patient, the GP who was asked to perform euthanasia called a colleague to consult with him about his patient with Amyotrophic Lateral Sclerosis (ALS).<sup>94</sup> It was unclear why Dr. Wilfred van Oijen picked this specific consultant. Was it because of his particular field of expertise or because the

<sup>87</sup> This is a difficult argument to make, but apparently not impossible. In her comments on a draft of this essay, Sigrid Sterckx argued that in religious-orthodox hospitals in Belgium euthanasia is not mentioned, and some older patients may not be aware of this option.

<sup>88</sup> Belgian Euthanasia Law, *supra* note 31, at Ch. 3, Sec. 4.

<sup>89</sup> R. COHEN-ALMAGOR, EUTHANASIA IN THE NETHERLANDS, *supra* note 1.

<sup>90</sup> Interview with Prof. Freddy Mortier, Ghent (Feb. 6, 2003).

<sup>91</sup> Interview with Prof. Freddy Mortier, Ghent (Feb. 14, 2005).

<sup>92</sup> Interview with Prof. Guido Van Steendam, Brussels (Feb. 5, 2003).

<sup>93</sup> Belgian Euthanasia Law, *supra* note 31, at Sec. 3.

<sup>94</sup> *Death on Request*, IKON, Interkerkelijke Omroep Nederland, Postbus 10009, 1201 DA Hilversum. I thank IKON for sending me a copy of this film. For deliberation and critique of the content of this film, see HERBERT HENDIN, *SEDUCED BY DEATH* 114-20 (1997).

physician knew this doctor and assumed that he would back his decision without too many questions? From the tone of the discussion, it seemed that the two doctors knew one another quite well and were on friendly terms. What worried me was that the requirement to consult may become a “dead dogma,”<sup>95</sup> used only to fill in the reports, and that, in essence, one hand simply washes the other: you approve euthanasia for my patients, and I will approve it for yours. Obviously, a doctor who approves of euthanasia would not call a colleague that is against it or is hesitant about the practice. Indeed, one Dutch study showed that the consultant was nearly always a partner in the practice or locum. At least 60 percent of the “independent consultants” giving the second opinion already knew the patient before the consultation. In only five percent of the cases did the family doctor seek a second opinion from a doctor whom he did not know personally.<sup>96</sup> Another Dutch study showed, unsurprisingly, that almost all consultants regarded the request of the patient to be well-considered and persistent, conceded that there were no further alternative treatment options, and agreed with the intention to perform euthanasia or assisted suicide. In general, the GPs did not need to change their views or plans following the consultation.<sup>97</sup> My own study showed that at least to 2003, Dutch consultants often were not independent from the physician who was asking for their opinion.<sup>98</sup> The situation may have changed since then as more and more physicians utilize the committee of specialists, SCEN, created for consultation on end-of-life issues.

Addressing this issue, Mortier said that there are no rules regarding the choice of the consultant. The only requirement is that the consultant must be independent. Mortier thinks that probably doctors approach like-minded physicians. It is not clear what happens if there is disagreement between doctors.<sup>99</sup> This issue deserves attention and study.

The euthanasia law speaks of considering with the patient the availability and consequences of palliative care. I wondered to what extent palliative care is a developed practice in Belgium. In the Netherlands, criticisms were raised that euthanasia came at the expense of adequate palliative care. Critics argued that there was no room for both concepts to develop simultaneously; as euthanasia became an accepted practice, palliative care was pushed aside. Until the late 1990s, Dutch GPs were not equipped to decide on the various alternatives designed to alleviate suffering. New developments in the field were not adopted, and progress in palliative care was quite neglected.<sup>100</sup> Thus, I wondered whether the situation in Belgium was better.

<sup>95</sup> Cf. JOHN STUART MILL, ON LIBERTY 95 (1948) (ch. 2 entitled “Utilitarianism, Liberty and Representative Government”).

<sup>96</sup> G. van der Wal et al., *Euthanasia and Assisted Suicide, II, Do Dutch Family Doctors Act Prudently?* 9 FAM. PRAC. 113, 115 (1992).

<sup>97</sup> Bregje Dorien Onwuteaka-Philipsen, *Consultation of Another Physician in Cases of Euthanasia and Physician-Assisted Suicide* 29, 31 (1999) (unpublished doctoral thesis, Amsterdam: Vrije Universiteit) (on file with author).

<sup>98</sup> R. COHEN-ALMAGOR, EUTHANASIA IN THE NETHERLANDS, *supra* note 1.

<sup>99</sup> Interview with Prof. Freddy Mortier, Ghent (Feb. 6, 2003).

<sup>100</sup> R. Cohen-Almagor, *Dutch Perspectives on Palliative Care in the Netherlands*, 18 ISSUES IN LAW & MED. 111 (2002). For further discussion, see Annemieke Kuin, Annemie M. Courtens, Luc Deliens

Luc Deliens answered that as in all other countries in the world, palliative care was a relatively new care concept and there was a lack of optimal resources for such care.<sup>101</sup> Likewise, Vincent and Barre said that physicians needed to improve their knowledge of palliative care. At the same time Vincent argued that there should not be a palliative care specialty. The school of medicine in Brussels did not think that palliative care should be a speciality. For him, speaking of palliative care was a misnomer. He preferred to speak of continuous care.<sup>102</sup> On the other hand, Van Steendam argued that Belgium has had good palliative care and good hospices.<sup>103</sup> Laterre maintained that palliative care was improving all the time as the government provided resources for this. In his opinion, Belgium was ranked fifth or sixth in Europe after the Scandinavian countries.<sup>104</sup> Two years later, Laterre ranked palliative care in Belgium as “very good.” He emphasized that there was palliative care education in nursing schools. There were special units that were dedicated to provide palliative care in hospitals. Palliative care specialists participated in discussions about patients with physicians, nurses and psychologists.<sup>105</sup> Most disturbing is the knowledge that some physicians did not consult a palliative care specialist before administering life-shortening drugs in order to alleviate pain. Indeed, in four recorded cases they did not consult any other health care personnel.<sup>106</sup>

Section 3 also stipulates that the patient’s request must be made in writing. However, research indicates that Flemish doctors frequently disregard this issue and do not obtain the patient’s request to end her life.<sup>107</sup> There is a need for data about the behavior of the Walloon doctors.

---

et al., *Palliative Care in the Netherlands: A Nationwide Evaluation Study*, 27 *J. PAIN & SYMPTOM MGMT.* 53 (2004).

<sup>101</sup> Interview with Prof. Luc Deliens, Brussels (Feb. 17, 2005).

<sup>102</sup> Interview with Prof. Jean-Louis Vincent and Dr. J. Berre, Erasme Hospital, Brussels (Feb. 6, 2003). Conversely, in the United States palliative care was recognized as a subspecialty by the American Board of Medical Specialties and certified by the Accreditation Council for Graduate Medical Education. The number of fellowship programs is increasing rapidly to help meet the demand. See Timothy E. Quill, *Legal Regulation of Physician-Assisted Death – The Latest Report Cards*, 356 *NEW ENG. J. MED.* 1911 (2007).

<sup>103</sup> Interview with Prof. Guido Van Steendam, Brussels (Feb. 5, 2003). See also Bert Broeckaert & Rien Janssens, *Palliative Care and Euthanasia: Belgian and Dutch Perspectives*, 9 *ETHICAL PERSPECTIVES* 156 (2002); S. Bauwens & W. Distelmans, *TOPAZ: First Palliative Day Care Centre in Belgium*, *HOSPICE BULL.*, vol. 9, no. 3, 2001, at 1-2; W. Distelman et al., *Palliative Day Care in Belgium: From Terminal Care towards Care for Incurable Patients*, 18 *PALLIATIVE MED.* 375 (2004); W. Distelmans et al., *Palliative Day Care in Belgium: First Observations*, 12 *EUR. J. PALLIATIVE CARE* 170 (2005).

<sup>104</sup> Interview with Prof. Pierre-François Laterre, Brussels (Feb. 5, 2003). See PAUL SCHOTSMANS & TOM MEULENBERGS, *EUTHANASIA AND PALLIATIVE CARE IN THE LOW COUNTRIES* (2005).

<sup>105</sup> Interview with Prof. Pierre-François Laterre, Brussels (Feb. 16, 2005).

<sup>106</sup> Veerle Provoost et al., *The Use of Drugs With a Life-Shortening Effect in End-of-life Care in Neonates and Infants*, 32 *INTENSIVE CARE MED.* 136 (2006). For further deliberation, see Jan L Bernheim et al., *Development of Palliative Care and Legalisation of Euthanasia: Antagonism or Synergy?* 336 *BRIT. MED. J.* 864 (2008), available at <http://www.medicalnewstoday.com/articles/104629.php>.

<sup>107</sup> Freddy Mortier & Luc Deliens, *The Prospects of Effective Legal Control of Euthanasia in Belgium: Implications of Recent End of Life Studies*, in *REGULATING PHYSICIAN-NEGOTIATED DEATH* 180 (A. Klijn, M. Otlowski & M. Trappenburg eds., 2001).

Section 4 of the law states that in anticipation of the eventuality when she would no longer be able to express her wish, every capable adult or emancipated minor may leave a written declaration of her wish that a physician should perform euthanasia when: (1) she is the victim of a serious and incurable accidental or pathological condition; (2) she is unconscious; and (3) this constitutes an irreversible situation in the current state of scientific knowledge.<sup>108</sup>

In this context, my concern lies with patients in a state of prolonged unawareness. These severely ill people who are in the twilight zone between life and death constitute an ethical and moral dilemma for all those involved in deciding their destinies: families, their loved ones, the medical staff, ethics committees, and sometimes the courts. The term describes a unique disorder in which patients who emerge from coma appear to be awake, but show no signs of awareness. There is an important distinction between patients in *prolonged* and/or *persistent* unawareness, as opposed to *permanent* unawareness. Physicians tend to confuse the two categories and conclude, sometimes prematurely, that there is no hope of regaining consciousness for patients in prolonged unawareness.<sup>109</sup> Most lay persons know nothing about these distinctions and gain their knowledge from the media that, generally speaking, are not interested in the medical intricacies and term those patients “vegetables.” No one would like to be in a state of a carrot or a potato, thus people may express a wish not to be treated if they enter such a state. The unethical terms “Vegetable” and “Persistent Vegetative State” (PVS) are frequently used to describe the condition of patients in a state of prolonged unawareness, but there are different parameters that we must take into account when coming to evaluate the condition of each individual patient. We must be aware of the variations that led to this situation, the condition of each patient, his or her age, how much time elapsed since the onset of the condition, brain activity, and other relevant criteria.<sup>110</sup> We must resist the temptation of resorting to a single criterion simplified by a special confusing and ethically problematic term that was coined—PVS—which might lead to treating patients unjustly.<sup>111</sup> The question is how much time should be given to patients in such a condition to regain consciousness. Cognitive recovery after six months is extremely rare in patients *older* than fifty years who underwent a traumatic episode (e.g., vehicle accident).<sup>112</sup> My independent research in Israel, Canada, the United States, the Netherlands and England brought me to suggest that we should

---

<sup>108</sup> Belgian Euthanasia Law, *supra* note 31, at Ch. 3, Sec. 4.

<sup>109</sup> Steven Laureys, *Death, Unconsciousness and the Brain*, 6 NATURE REV./NEUROSCIENCE 903 (2005).

<sup>110</sup> Adrian M. Owen et al., *Detecting Awareness in the Vegetative State*, 313 SCIENCE 1402 (2006); Carl Zimmer, *What If There Is Something Going On in There?* N.Y. TIMES, Sept. 28, 2003; Gastone G. Celesia, *Persistent Vegetative State: Clinical and Ethical Issues*, 18 THEORETICAL MED. 222 (1997).

<sup>111</sup> R. Cohen-Almagor, *Language and Reality at the End of Life*, 28 J. L. MED. & ETHICS 267 (2000). See also S.E. Bedell et al., *Words That Harm, Words That Heal*, 164 ARCH. INTERNAL MED. 1365 (2004); J.T. Giacino et al., *The Minimally Conscious State*, 58 NEUROLOGY 349 (2002).

<sup>112</sup> Council on Scientific Affairs and Council on Ethical and Judicial Affairs, *Persistent Vegetative State and the Decision to Withdraw or Withhold Life Support*, 263 JAMA 426, 428 (1990).

adopt a two-year waiting policy with patients who are younger than fifty years old and whose condition was caused by trauma. Withdrawal of therapy from patients in prolonged unawareness *younger* than fifty years old could take place after two years provided the patients' loved ones have given their consent and the patient's condition has remained static during those two years.<sup>113</sup> My fear is that in Belgium, where euthanasia and quality-of-life considerations are prominent, patients may express a general wish to die upon entering such a condition, and this request will be honored prematurely. Moreover, poor prognosis of some patients in prolonged unawareness might result in failure to receive adequate rehabilitative care early on. Improvement in their condition may require long months of continuous treatment and this grace period might not be granted to them.

Another concern was that apparently too few doctors knew how to correctly carry out euthanasia. A study by the universities of Brussels and Ghent showed that doctors did not always use the most suitable methods. An investigation was carried out on twenty-two cases of euthanasia in 1998. At that time euthanasia was still illegal, but it seems as though little has changed since then. Only four of the twenty-two cases were handled correctly. In about a half of the cases morphine was employed. Morphine does not necessarily cause death. Robert van der Stichele and colleagues argued that the correct medication and procedure was readily available, but most doctors were ill-informed. Most physicians seemed unaware of procedures for guaranteeing a quick, peaceful, and certain death.<sup>114</sup> Indeed, Freddy Mortier speaks of the need for medical education because doctors are not aware of the drugs that should be used.<sup>115</sup> Wim Distelmans, on the other hand, disagrees. In his comments he wrote that this concern was certainly true before the law, but "nowadays most physicians know what products to be used" or where they can find the right information (e.g., LEIF-physicians; [www.leif.be](http://www.leif.be)).<sup>116</sup>

## Post-Law Developments – Further Concerns

### *Mario Verstraete*

Exactly a week after the euthanasia law went into effect, September 30, 2002, 39-year-old Mario Verstraete, who suffered from multiple sclerosis, died by lethal injection. Critics complained that the new law was broken on several counts and called for the prosecution of the doctor who assisted his death. Under the new law, at least one month must elapse between a written death request and the euthanasia, the idea being to give the patient a chance to change his or her mind. But Verstraete was dead within seven days after the introduction of the new law. Furthermore,

---

<sup>113</sup> R. Cohen-Almagor, *Some Observations on Post-Coma Unawareness Patients and on Other Forms of Unconscious Patients: Policy Proposals*, 16 *MED. & L.* 451 (1997), and *THE RIGHT TO DIE WITH DIGNITY*, *supra* note 1.

<sup>114</sup> R.H. Vander Stichele et al., *Drugs Used for Euthanasia in Flanders, Belgium*, 12 *PHARMACOEPIDEMIOLOGY & DRUG SAFETY* 1 (2003).

<sup>115</sup> Interview with Prof. Freddy Mortier, Ghent (Feb. 6, 2003).

<sup>116</sup> Prof. Wim Distelmans, personal communication (July 2, 2007).

there were questions whether the patient received a second medical opinion, as is required under the law. Moreover, the fact that he was not in the final stages of a terminal illness (although suffering considerably) also angered sceptics. The new law does make provision for patients who are not in the final phases of a terminal illness, but their doctor must get a second opinion, and it was unclear whether Verstraete's doctor complied with that requirement.<sup>117</sup> The National Evaluation and Control Commission for Euthanasia decided not to intervene. It estimated that the patient had asked for euthanasia many months before the euthanasia was legalized, and that he had expressed his wish to die sufficiently, also in public and in the national media.<sup>118</sup> Indeed, the case received ample publicity before and after Verstraete's death as Verstraete, a longstanding campaigner for legalizing euthanasia, appeared in a broadcast by Dutch language television on the evening he died, and explained what he intended to do, who would be with him, and the funeral arrangements he had made.<sup>119</sup>

Verstraete clearly wanted to die; hence the breach of the law did not constitute abuse. Still it is disturbing that only a week after the passing of the law and in the very first case the physician did not adhere to the euthanasia law guidelines.

### **Suzanne Roegiest**

In February 2006 Marc Cosyns, a GP as well as a lecturer in end-of-life care at the University of Ghent, ignited further debate when he published an article in the medical magazine *Huisarts* stating that he had ended the life of Suzanne Roegiest on January 20, 2006.<sup>120</sup> Roegiest was an 87-year-old dementia patient. Cosyns gave his patient a lethal drink and she died shortly after. But the law requires patients to be in full possession of their mental powers before they can consent to euthanasia. Legislation attempts to extend euthanasia to patients who are legally incapable of expressing their will were stalled in the Senate, and Cosyns wished to push the agenda forward. He argued that Mrs. Roegiest had asked in a "lucid" moment to be allowed to die and that he had given her a drink containing barbiturates.<sup>121</sup> Strictly speaking her death could be seen as a form of suicide, because she drank from the cup herself. The case came before the public prosecution office which decided that Cosyns did not break the law.

Dementia does not qualify as unbearable suffering. It is not very convincing to speak of the "lucid moments" of dementia patients when seeking to justify euthanasia

<sup>117</sup> Andrew Osborn, *Belgian Outcry Over First Mercy Killing Under New Law*, *GUARDIAN*, Oct. 9, 2002.

<sup>118</sup> Interview with Prof. Freddy Mortier, Dean of Faculty of Arts and Philosophy, Ghent University (Feb. 14, 2005).

<sup>119</sup> Rory Watson, *First Belgian To Use New Euthanasia Law Provokes Storm of Protest*, 325 *BRIT. MED. J.* 854 (2002).

<sup>120</sup> Marc Cosyns, *The Family Doctor*, *HUISARTS*, Feb. 9, 2006, at 6-7.

<sup>121</sup> Jane Burgermeister, *Doctor Reignites Euthanasia Row in Belgium After Mercy Killing*, 332 *BRIT. MED. J.* 382 (2006). See also Veronica English et al., *Ethics Briefings*, 32 *J. MED. ETHICS* 371 (2006).

or PAS. Demented patients may become very lucid and then slip back into a severe state of dementia and incompetence. The “lucid moments” are in flux, and the following moments might be very different. The patient’s wishes might be contrary to those expressed during the time the patient was allegedly lucid and competent enough to make a decision. Demented patients are unable to make an autonomous and informed request and should for this reason be excluded from euthanasia. The Dutch Alzheimer Foundation warned: “Dementia itself could never be a reason for assisted suicide because the patient is incapable of making an informed request.”<sup>122</sup> Furthermore, Dutch doctors, on the whole, do not respect euthanasia requests of demented patients because they feel honoring such a request betrays their obligation to help these patients.<sup>123</sup> The “treatment” of demented patients is not to kill them, but rather investing in them, caring for them, providing them with compassion and attention.<sup>124</sup> Palliative care, management, and educational strategies are needed to improve end-of-life care in advanced dementia.<sup>125</sup>

Luc Deliens and Freddy Mortier did not believe that allowing euthanasia for demented patients would be allowed by the law. Deliens explained that the law is based on self-determination. For this same reason, it would not include terminating the lives of neonates. Deliens said: “We need to speak about these issues, but legalization is not the recipe for everything. Some issues cannot be solved by law.”<sup>126</sup> Deliens suggested devising a set of guidelines on end-of-life treatments for various categories of patients, including dementia. Mortier thought physicians would not conduct euthanasia for demented patients.<sup>127</sup>

Marc Cosyns likes to provoke and to attract attention by using controversy. On June 29-30, 2007, Cosyns stated that he intended to perform an illegal form of euthanasia on an older patient. Veerle Provoost who brought the issue to my attention stated that the two issues that made this case illegal were: (1) Cosyns refused

<sup>122</sup> R. Cohen-Almagor, *EUTHANASIA IN THE NETHERLANDS*, *supra* note 1, at 119.

<sup>123</sup> However, in 2004, the Netherlands reported for the first time a case of a doctor complying with a request for assisted suicide from a patient with Alzheimer’s disease. The report stated that, in general, patients with Alzheimer’s disease could not always comply with the requirements but that “in specific circumstances” they could. The 65 year old patient had had Alzheimer’s disease for three years. Since his diagnosis he had said that he did not wish to endure the full course of his illness and had in the previous year repeatedly asked for help to commit suicide. The doctor judged him to be suffering unbearably. He was conscious that he could no longer function independently and faced the future prospect of increasing dementia. Tony Sheldon, *Dutch Approve Euthanasia for a Patient With Alzheimer’s Disease*, 330 *BRIT. MED. J.* 1041 (2005).

<sup>124</sup> R. Cohen-Almagor, *EUTHANASIA IN THE NETHERLANDS*, *supra* note 1, at 156-61. *See also* R. COHEN-ALMAGOR, *THE RIGHT TO DIE WITH DIGNITY*, *supra* note 1, at ch. 5.

<sup>125</sup> Susan L. Mitchell et al., *Dying with Advanced Dementia in the Nursing Home*, 164 *ARCHIVES INTERNAL MED.* 321 (2004). For further discussion, *see* Ron Berghmans, *Advance Directive in Dementia*, in *MEDICAL ETHICS AT THE DAWN OF THE 21ST CENTURY* 105-10 (R. Cohen-Almagor, ed., 2000).

<sup>126</sup> Interview with Prof. Luc Deliens, Department of Medical Sociology and Health Sciences, Free University of Brussels (Feb. 17, 2005).

<sup>127</sup> Interview with Prof. Freddy Mortier, Ghent (Feb. 14, 2005). *See also* [http://alzheimers.org.uk/site/scripts/home\\_info.php?homepageID=29](http://alzheimers.org.uk/site/scripts/home_info.php?homepageID=29).

to report the case to the Euthanasia Commission for review, and (2) he refused to consult a second physician. In an interview on the VRT television news, Cosyns said he wished to point out that the euthanasia law was too narrow, and that palliative care was not included in it. Together with Provoost, I find Cosyns's behavior a very curious way of trying to improve things. Slowly he builds a reputation that is reserved to euthanasia zealots who are willing to disregard law and to cut corners in order to advance their agenda. Jack Kevorkian has spent many years in jail for doing just that.<sup>128</sup>

### **Newborns**

Another cause for concern is physicians' attitudes toward euthanizing newborns. A 2005 survey of Flanders doctors revealed three in four were willing to shorten the life of critically-ill babies. Veerle Provoost and colleagues examined the medical files of 292 babies. They also questioned the acting physicians about the exact cause of death, whether the decision was intended to hasten death, and how much they estimated life was shortened.<sup>129</sup>

The response rate was 87 percent; 254 questionnaires were returned. End-of-life decisions were implicated in 194 deaths. Over the course of a year, a medical decision preceded death in 143 cases. The majority involved withdrawing or withholding treatment. In seventeen deaths, high doses of painkillers were explicitly administered to end the newborn's life. Administering lethal drugs to minors is against the law. Still, of 121 doctors questioned, 79 percent thought it was their "professional duty" to prevent unnecessary suffering by hastening death. The vast majority (88 percent) also accepted quality-of-life ethics. Fifty-eight percent supported the legal termination of life in some cases.<sup>130</sup>

In actual practice, in 84 percent of the cases, the decision was made in consultation with the parents. In twenty-two deaths parents were not consulted. In seventeen cases physicians stated that the situation was so obvious that there was no reason to consult the parents. In one case lack of time to consult the parents was given as a reason. In three cases the physician reported that the parents had stated a wish to hasten the end of life at some point during treatment. For one death no reason is supplied in the study.<sup>131</sup>

---

<sup>128</sup> See <http://www.pbs.org/wgbh/pages/frontline/kevorkian/>; <http://www.fansoffieger.com/kevo.htm>; and [http://www.reuters.com/article/domesticNews/idUSN0726831020070601?src=060107\\_1054\\_DOUBLEFEATURE\\_](http://www.reuters.com/article/domesticNews/idUSN0726831020070601?src=060107_1054_DOUBLEFEATURE_); <http://www.internationaltaskforce.org/jk.htm>.

<sup>129</sup> Veerle Provoost et al., *Medical End-of-Life Decisions in Neonates and Infants in Flanders*, 365 LANCET 1315 (2005).

<sup>130</sup> *Id.* at 1319. See also *Doctors "Would Help Babies to Die,"* EVENING STANDARD, Apr. 8, 2005; available at [right\\_to\\_die\\_2@mailman.efn.org](mailto:right_to_die_2@mailman.efn.org); and *Baby Euthanasia Is a Reality*, EXPATICA, Apr. 11, 2007.

<sup>131</sup> Veerle Provoost et al., *Consultation of Parents in Actual End-of-life Decision-making in Neonates and Infants*, 165 EUR. J. PEDIATRICS 859 (2006). See also V. Provoost et al., *A Classification of End-of-life Decisions in Neonates and Infants*, 93 ACTA PAEDIATRICA 1 (2004). For an opposing viewpoint, see Chris Feudtner, *Control of Suffering on the Slippery Slope of Care*, 365 LANCET 1284 (2005).



Comparison between end-of-life decision-making in Belgium and in the Netherlands shows that the practice regarding severely-ill neonates and infants is rather similar. Furthermore, parents and colleague physicians are more often involved in the decision making in the Netherlands.<sup>132</sup> Given my criticisms of the Dutch practice,<sup>133</sup> I think Belgium should also invest more time examining these issues and preventing abuse and unnecessary death.

## Monitoring

### *The First Report*

In September 2004, the first major study into the effect of Belgium's new legislation that permits euthanasia found that every month some twenty terminally-ill patients asked doctors to help them to die. The study, drawn up by a special federal commission tasked with assessing the impact of the September 2002 law, found that 259 acts of legal euthanasia were carried out in Belgium through the end of 2003. The Federal Control and Evaluation Commission for Euthanasia counted an average of seventeen registered cases of euthanasia per month. About 60 percent of euthanasia cases were administered in hospitals; the rest usually took place at the patients' homes. The vast majority of people asking to be allowed to die with dignity were suffering from terminal cancers. Euthanasia was reported more often in Dutch-speaking Flanders than in Francophone Wallonia. Of the 259 declared acts of euthanasia, 216 or 83 percent were written in Dutch. Only forty-three declarations, just 17 percent of the total, were made in French.<sup>134</sup> Pierre-François Laterre, Director of ICU at St. Luc Hospital in Brussels, explained that the Flemish, who are mostly Catholic, are more open in reporting their euthanasia practice than the French-speaking (in Laterre's words, "not because they want to hide it, but because they hate respecting laws in general ... Latin approach"). All put emphasis on quality of life as playing the biggest role in any decision regarding the introduction and the withdrawal of care.<sup>135</sup> Guido van Steendam further maintained that in the south of Belgium, French-speaking people rely on doctors, while in Flanders, people focus more on autonomy.<sup>136</sup> Another possible reason has to do with the establishment of LEIFartsen (Life End Information Forum) in Flanders. According to the conclusion of the first report of the Federal National Evaluation and Control Commission for

---

<sup>132</sup> Astrid M. Vrakking et al., *End-of-life Decision Making in Neonates and Infants: Comparison of the Netherlands and Belgium (Flanders)*, 96 *ACTA PAEDIATRICA* 820 (2007). For further discussion, see Astrid M. Vrakking et al., *Medical End-of-Life Decisions Made for Neonates and Infants in the Netherlands, 1995-2001*, 365 *LANCET* 1329 (2005); Alexander A. Kon, *We Cannot Accurately Predict the Extent of an Infant's Future Suffering: The Groningen Protocol is too Dangerous to Support*, 8 *AM. J. BIOETHICS* 27 (2008).

<sup>133</sup> R. COHEN-ALMAGOR, *EUTHANASIA IN THE NETHERLANDS*, *supra* note 1; and *THE RIGHT TO DIE WITH DIGNITY*, *supra* note 1, at ch. 7.

<sup>134</sup> "ERGO," available at [ergo@efn.org](mailto:ergo@efn.org) (Sept. 16, 2004).

<sup>135</sup> Interview with Prof. Pierre-François Laterre, Brussels (Feb. 16, 2005).

<sup>136</sup> Interview with Prof. Guido van Steendam, Director, Biophilosophy Center, STARLAB, Brussels (Feb. 5, 2003).

Euthanasia, the LEIFartsen-platform may be the reason for the much higher willingness for registration of euthanasia-cases by the Flemish physicians in contrast with their Walloon colleagues.<sup>137</sup>

In February 2003, a platform was founded in Flanders of approximately 200 physicians with special training in end-of-life care (with special attention to palliative care) and ethical decisionmaking (including euthanasia, palliative sedation and withdrawal/withholding of futile treatment). The participating physicians are called LEIFartsen and include both GP's and specialists working in hospitals. The training is interdisciplinary and is very similar to the formation of SCEN artsen (the Dutch equivalent in The Netherlands).<sup>138</sup>

### **The Second Report**

In December 2006, the Federal National Evaluation and Control Commission for Euthanasia issued its second report, covering the period 2004-2005. This report dealt with 742 legal euthanasia cases, thirty-one per month, a significant increase compared with the 2002-2003 figures when only seventeen euthanasia cases per month took place. The overall findings of this report were that 83 percent of cases involved cancer patients. In these cases the physicians estimated that the patients were, for the most, unlikely to live for more than a few months. Seventy-seven percent of cases affected persons between 40 and 79 years of age. The main age-groups are people in their 40's and people over 80. People over 80 constitute a mere 17 percent of all euthanasia cases while they represent more than a half of non-assisted death. Forty-five percent of cases were dealt with by the GP at the patient's home.<sup>139</sup> Only 14 percent of all declarations were written in French. Eighty-six percent of the declarations were written in Flemish and euthanasia was preformed in Flanders.<sup>140</sup> These findings echo the results of the first report. I reiterate that more should be said about the *reasons* for the differences between the Dutch-speaking and French-speaking parts of Belgium and more research should be carried out in Wallonia. Not

---

<sup>137</sup> See <http://www.makeevent.it/ScientificProgrammeScheme/participationAbstract.jsp?id=27958> (last accessed on July 21, 2007, no longer available). See also Wim Distelmans et al., *Life End Information Forum-Physicians (LEIFartsen): Improvement of Communication Skills in End-of-Life Issues Among Physicians*, 15 PSYCH. ONCOLOGY 226 (2006); Reginald Deschepper et. al, *Communication on End-Of-Life Decisions with Patients Wishing to Die at Home: The Making of a Guideline for GPs in Flanders, Belgium*, BRIT. J. GEN. PRAC., Jan. 1, 2006, at 14, available at <http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=1828069>.

<sup>138</sup> Tony Sheldon, *Netherlands Sets Up Euthanasia Advisory Body*, 318 BRIT. MED. J. 348 (1999). Luc Deliens explained that while in the Netherlands SCEN doctors help only general practitioners, Leifartsen doctors also help medical specialists in the hospitals. There is an interest to involve them in hospital consultations as well. Interview with Prof. Luc Deliens, Department of Medical Sociology and Health Sciences, Free University of Brussels (Feb. 17, 2005).

<sup>139</sup> THE NEWSLETTER OF RIGHT-TO-DIE EUROPE, available at [org.opn.lists.right-to-die@lists.opn.org](mailto:org.opn.lists.right-to-die@lists.opn.org) (Jan. 17, 2007).

<sup>140</sup> *Belgium Keeps Tight Reins on Euthanasia Legislation*, EXPATICA, available at [org.opn.lists.right-to-die@lists.opn.org](mailto:org.opn.lists.right-to-die@lists.opn.org) (Nov. 9, 2006).

much is known about the views of the French-speaking doctors on the euthanasia practice of their Flemish colleagues. There is room for much more research about the relationships between the two parts of Belgium.

### Conclusions and Suggestions

Medical experts argue that the number of mercy killings carried out in Belgium have actually remained relatively constant and that the main difference since the enactment of the new law was that doctors no longer had to carry out illegally a service that some of their terminally-ill patients requested.<sup>141</sup> However, this study shows that Belgium still has a lot to do in order to enforce its policy and effectively circumscribe the practice of euthanasia.

Some of my interviewees said that the euthanasia debate is over. In Belgian society, quality-of-life is important. Euthanasia is what the people want and now politicians are studying the situation before they would opt to introduce further changes. The government does not think there is a problem with the euthanasia practice. It wishes to have quiet, to remove the subject from the public agenda.<sup>142</sup> The government seems to think the job has been completed, whereas in practice it has just started.

Wim Distelmans, on the other hand, does not think that the debate is over. On the contrary, he said that the current debate is on the extension of the law towards minors and adults affected by damaged brain functions (e.g., cerebral metastases and dementia).<sup>143</sup> In December 2008, Jean-Louis Vincent wrote to me saying that both issues are now being discussed.<sup>144</sup> Both issues are highly controversial and problematic. It is incumbent upon democratic governments to protect the best interests of vulnerable third parties. I hope the Belgian parliament will invest time and thoughtful consideration before drawing any conclusions.

Much of the practice of euthanasia is dependent on the general practitioners. Physicians need to remain aware of the very powerful role their recommendations can play in people's treatment choices, and of the undue ways their recommendations can influence patients. This is especially true when physicians and patients have long-standing relationships that span decades. The challenge for physicians is to use their influence for the best purposes. It is important to get patients to talk out loud about their values before making treatment recommendations. Often, this type of conversation will make it easier for physicians to determine what recommendation is most appropriate for a patient and whether the patient is comfortable deciding what to do without receiving a recommendation. In the current atmosphere in Belgium, it would suffice to say: "I would be willing to assist you in every pos-

---

<sup>141</sup> ERGO," available at [ergo@efn.org](mailto:ergo@efn.org) (July 9, 2004).

<sup>142</sup> Interviews with Prof. Pierre-François Laterre and Prof. Luc Deliens, Brussels (Feb. 16-17, 2005).

<sup>143</sup> Wim Distelmans, personal communication (July 2, 2007).

<sup>144</sup> Personal communication (Dec. 10, 2008).

sible way, considering any of your wishes in order to relieve your suffering and help you cope with your condition.” We should recognize the compromising effect that the doctor’s initiation of discussion on euthanasia might have on the relationship with the patient and on the level of trust between the two parties, as well as on the patient’s mental framework.

The mixed views about palliative care, its role, importance, and practice in making decisions at the end of life provide a basis for concluding that there is room for improvement. Since 1991 I have been studying end-of-life issues. My research was not confined to libraries and research seminars. I visited dozens of hospitals and medical research centers in different countries: Israel, England, United States, Canada, Australia, New Zealand, the Netherlands, and Belgium. Most patients, according to testimonials of heads of departments and heads of ethics committees, cling to life no matter what. Even in the most miserable and painful situations, e.g. cancer, patients opt for life. This is hardly surprising given the alternative. In Jewish and Catholic hospitals I was told that 99 percent of patients cling to life. In less religious hospitals, 90 to 95 percent prefer to continue living. The majority of those who express a wish to die do this out of fear of suffering. Once physicians are able to control pain, many who had expressed a wish to die change their minds.<sup>145</sup> Thus we are left with a very small number of patients who wish to decide the moment of their death. These are strong-willed patients who emphasize autonomy and dignity. Medicine should serve *all* patients, not only the majority of them. But for the vast majority of patients, palliative care enjoys precedence over euthanasia. The two are not on equal footing. Only when palliative care fails to address the patient’s wishes and is unable to adequately mitigate the patient’s physical and mental suffering should physicians offer euthanasia.

At present, in the advent of the euthanasia law, physicians may resort to euthanasia too quickly without proper investigation and without taking advantage of the existing alternatives. Broeckaert and Janssens suggest the development of a palliative care filter defined as a consultation with a palliative support team about the possibilities of palliative care, to filter out what they call pseudochoices for euthanasia that result from poor care.<sup>146</sup>

It is advisable that the identity of *all* consultants be determined by a small committee of specialists (like “LEIFartsen”), who will review the requests for euthanasia. This is in order to avoid the possibility of quid pro quo arrangements between doctors (“you will consult for me regarding Mr. Van Bones, approving my decision, and I will consult for you regarding Ms. Brugge, approving your decision”).

---

<sup>145</sup> R. COHEN-ALMAGOR, *THE RIGHT TO DIE WITH DIGNITY*, *supra* note 1.

<sup>146</sup> Bert Broeckaert & Rien Janssens, *Palliative Care and Euthanasia: Belgian and Dutch Perspectives*, 9 *ETHICAL PERSPECTIVES* 156 (2002); Charlotte Verpoort et al., *Palliative Care Nurses’ Views on Euthanasia*, 47 *J. ADVANCED NURSING* 592, 598 (2004). Wim Distelmans noted in his comments that other experts think that the patient should be informed of the potential benefits of palliative care, but should not be forced to undergo a consultation with a palliative support team.

The present law lacks sufficient control and monitoring mechanisms in order to ascertain that no abuse is taking place. There must be extensive documentation in the patient's medical file, including the following: diagnosis and prognosis of the disease by the attending and the consulting physicians; attempted treatments; the patient's reasons for seeking physician-assisted suicide; the patient's request in writing or documented on a video recording; documentation of conversations with the patient; the physician's offer to the patient to rescind her request; documentation of discussions with the patient's loved ones; and a psychological report confirming the patient's condition to verify that the request does not stem from depression. This meticulous documentation is meant to prevent exploitation of any kind—personal, medical, or institutional. Each report should be examined by a coroner following completion of the physician-assisted suicide. Furthermore, pharmacists should also be required to report all prescriptions for lethal medication, thus providing a further check on physicians' reporting.

Laterre said that there is some monitoring of drugs sold and some inspection of prescriptions signed by physicians.<sup>147</sup> But "some" is not enough. There should be comprehensive monitoring of such drugs. All lethal drugs should be recorded in writing, and the remainder of lethal medication used for euthanasia should be returned to the same pharmacists who sold them, otherwise it might be used to kill another person as indeed happened in the Netherlands.<sup>148</sup> A 2002 study shows that pharmacists in Flanders favor guidelines drafted by their own professional organizations (95 percent) and enforced by legislation (90 percent) to ensure adequate safeguards for end-of-life practice. Before the enactment of the law, seven percent of the responding pharmacists in the study reported that they had been confronted with a prescription for drugs that in their judgment were exclusively intended to shorten the patient's life. No one referred the request to a colleague of a hospital pharmacy.<sup>149</sup> Since 2005, a few hundred pharmacies across Belgium began offering euthanasia kits (at a cost of 60 Euros) and are meant for physicians who perform euthanasia in patients' homes.<sup>150</sup> In 2006, the Belgian Pharmaceutical Association has finalized guidance for pharmacists on the Euthanasia Act and this describes in detail how lethal drugs should be prescribed, delivered, administered or returned if not used. It also includes information on how the products should be ordered and priced.<sup>151</sup>

---

<sup>147</sup> Interview with Prof. Pierre-François Laterre, Brussels (Feb. 16, 2005).

<sup>148</sup> See Dr. Van Oijen's conduct, as recorded in my book, *EUTHANASIA IN THE NETHERLANDS*, *supra* note 1, at 167-69.

<sup>149</sup> Johan Bilsen et al., *Physician-Assisted Death: Attitudes and Practices of Community Pharmacists in East Flanders, Belgium*, 19 *PALLIATIVE MED.* 151 (2005).

<sup>150</sup> Personal communication of Prof. Veerle Provoost (Jan. 16, 2009).

<sup>151</sup> Colin Meek, *Pharmacy Involvement Where Assisted Suicide and Euthanasia Are Permitted*, 277 *PHARMACEUTICAL J.* 615 (2006).

Furthermore, together with Deliens and Van der Wal, I believe that robust empirical research should be consistently done to assess the end-of-life care consequences of the legalization of euthanasia in Belgium.<sup>152</sup>

Finally, I would suggest that the local medical association should establish a committee, whose role will be not only to investigate the underlying facts that were reported, but also to investigate whether there are “mercy” cases that were not reported and/or that did not comply with the law. Licensing sanctions should be enforced to punish those health care professionals who violate the law, fail to consult or to file reports, engage in involuntary ending of life without the patient’s consent or with patients lacking proper decision-making capacity. Physicians who failed to comply with the provisions in the law should be charged and procedures to sanction them should be brought by the Disciplinary Tribunal of the Medical Association. The maximum penalty for violation of the law should be the revoking of the physician’s medical license. In the event that this penalty proves insufficient in deterring potential abusers, further penalties should be considered including heavy fines and prison sentences. Special attention should be given to the most vulnerable patients, e.g., those with dementia or other mental incapacity, newborns, and children. The conditions for euthanasia need to be clarified in detail, closing the door to possible misinterpretation that could lead to abuse. After all, what is at stake is a matter of life and death.

---

<sup>152</sup> L. Deliens & G. van der Wal, *The Euthanasia Law in Belgium and the Netherlands*, 362 LANCET 1239 (2003).

## **Appendix: Euthanasia in Belgium – Questionnaire**

1. Are you content with the Belgian practice of euthanasia?
2. What are the pros of the practice? What are the cons?
3. What do you think about the euthanasia law? Is the law too wide? Too narrow? OK in scope? Would you recommend adding or omitting something?
4. What do you think about the work of the Federal Commission of Control and Evaluation?
5. Section 3 of the Belgian Law says: the patient is an adult or an emancipated minor, capable and conscious at the time of his/her request. What does “emancipated minor” mean?
6. How many euthanasia cases are there every year?
7. Are there cases of PAS? How many each year?
8. Are there differences in attitude to euthanasia between the French-speaking Belgium and the Dutch-speaking Belgium?
9. The physician practising euthanasia is required to consult a colleague with regard to the hopeless condition of the patient. Who decides the identity of the second doctor?
10. Is consultancy by phone possible?
11. Is there room to assume that the doctor will approach a like-minded physician? Someone who would consent to the practice?
12. What is the reporting rate of euthanasia cases?
13. Are there euthanasia cases without the consent of the patient?
14. Are there fears of elderly people that their lives will be ended without their consent?
15. Do you have information about how many cases are there of families who request euthanasia for the patient?
16. How could the reporting rate be improved?
17. Do doctors keep record of euthanasia cases?
18. Should doctors suggest euthanasia to their patients?
19. How would you rate the practice of palliative care in Belgium?
20. How should the medical profession deal with ADs for demented patients?
21. The practice of “terminal sedation”: What do you know and think of it?

22. Are pharmacists required to report of selling medication required for euthanasia? Why?
23. Other developments and concerns?
24. Important legal precedents?