

BOOK REVIEW

DIGNITY, COMPASSION, CARE, AND SAFETY VALVES AT THE END-OF-LIFE

Marc Groenhuijsen and Floris van Laanen (eds.),
EUTHANASIA IN INTERNATIONAL
AND COMPARATIVE PERSPECTIVE

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I. Introduction

Since the second half of the 20th Century, there is a growing concern regarding the role of medicine in our lives. As technology progresses, and medical knowledge and expertise advance, the technological ability to sustain and prolong life improved tremendously. This advancement of technology evoked new ethical questions at the end of life: Should life be sustained no matter what, notwithstanding the condition of the patient, his/her wishes and his/her quality of life? Who should decide when to stop treatment? Can a patient decide when his/her life comes to an end? What is the role of autonomy, self-determination, and informed consent in the decision-making process? What is the role of the physician?

These and other questions occupy the thinking of philosophers, bioethicists, lawyers as well as of decision-makers: legislators, government officials, and judges. Although

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the general publics in many democracies, including the United States,¹ England,² Australia,³ Canada,⁴ and Croatia⁵ believe that life should not be prolonged at all costs, and that the law should cater to the patients' wishes at the end of life, most countries in the world refrained from legislation upholding mercy killing (euthanasia, direct act aimed to bring life to an end) and physician-assisted suicide by which a physician prepares lethal medication, usually put it in pudding, and the patient does the last act, taking his or her own life (PAS in short). The only exceptions are The Netherlands, the first country in the world to legislate euthanasia in April 2002,⁶ Belgium that went the same way as its neighbour shortly afterwards,⁷ Luxembourg that became third EU country to allow euthanasia,⁸ Switzerland that permits aiding the dying by laypersons since 1937 (under Article 115 of the Penal Code),⁹ the Northern Territory in Australia that legislated PAS in 1995 (Rights of the Terminally Ill Act 1995 NT), but the law that came into effect in July 1996 was annulled in March 1997,¹⁰ and the State of Oregon in the U.S. that legislated PAS under the Death with Dignity Act.¹¹

¹ Joseph Carroll, *Public Continues to Support Right-to-Die for Terminally Ill Patients*, GALLUP NEWS SERVICE, June 19, 2006; Humphrey Taylor, *Poll: U.S. Adults Favor Euthanasia and Physician Assisted Suicide*, PRNEWswire, Apr. 27, 2005.

² Lucy Ward & John Carvel, *Four Out of Five Want to Give Doctors Right to End Life of Terminally Ill Patients in Pain*, THE GUARDIAN, Jan. 24, 2007, at 9.

³ ERGO News List, discussion group on end-of-life (Mar. 4, 2007).

⁴ THE OTTAWA CITIZEN (Canadian daily) (July 2, 2001).

⁵ EUTHANASIA IN INTERNATIONAL AND COMPARATIVE PERSPECTIVE 70 (Marc Groenhuijsen & Floris van Laanen eds., 2006) [hereinafter EUTHANASIA IN INTERNATIONAL AND COMPARATIVE PERSPECTIVE].

⁶ Termination of Life on Request and Assisted Suicide (Review Procedures) Act, available at http://www.academivita.org/english/AltriDocumenti/org_int/OLANDA/Testo%20legge%20olandese%20eutanasia%5B1%5D.pdf.

⁷ Jacqueline Herremans, *Belgium's Legalization of Euthanasia*, available at <http://www.iheu.org/node/1110>.

⁸ On February 19, 2008 the Parliament of Grand Duchy of Luxembourg approved the bill Errr/Huss on de-criminalization of euthanasia. While the euthanasia bill has not yet passed the second reading, it is anticipated that it will come into effect this summer, unless the parliament's opinion changes radically. See John Connolly, *Luxembourg Parliament Passes Euthanasia Bill*, LIFESITENEWS.COM, Feb. 20, 2008, available at <http://www.lifesitenews.com/ldn/2008/feb/08022002.html>.

⁹ Swiss Penal Code, art. 115, discusses inciting and assisting suicide and holds: "Anyone with a selfish motive who incites a person to commit suicide or who helps that person to commit suicide, if the suicide is consummated or attempted, will be punished by a maximum of five years reclusion or imprisonment." If there is no selfish motive, assisted suicide is legal. I am grateful to EXIT A.D.M.D Suisse Romande for this information: exit@freemail.ch. Cf. http://www.bk.admin.ch/ch/fr/rs/311_0/index2.html. See also <http://www.exit-geneve.ch/Exitdepangl.pdf>.

¹⁰ 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. (Spring 1997).

¹¹ Death with Dignity Act, (Ballot Measure 16 (1994)) (the law came into effect in 1997), see <http://oregon.gov/DHS/ph/pas> and see <http://www.oregon.gov/DHS/ph/pas/docs/statute.pdf>.

Thus, when I saw the title of this book, *Euthanasia in International and Comparative Perspective*, I was a bit puzzled. The confusion grew as I looked at the table of contents. It speaks of no less than fourteen jurisdictions: Belgium, The Netherlands, the USA (curiously, Oregon's Measure No. 16 is hardly mentioned in this chapter), Croatia, Finland, France, Germany, Greece, Iran, Israel, Italy, Japan, Poland, and Spain. Most of these countries do *not* allow their physicians to take active steps to shorten lives. Chapters on Switzerland, Luxemburg and Australia are sorely missing.

By presenting the rules regulating euthanasia in the fourteen above-mentioned countries, the book aims at giving a comprehensive picture of this delicate problem in today's world. In order to do so, it focuses first and foremost on definitional issues. In comparative perspective, the book shows that there is no shared definition of euthanasia: quite the opposite, the distinctions made across countries between active and passive, direct and indirect, voluntary and non-voluntary euthanasia create a complex and multifaceted legal picture.

Secondly, the book deals with the crucial aspect of end-of-life decision-making, namely the definition of the will of the patient. Whereas the right to request medical treatment is virtually undisputed the situation becomes more complicated when it comes to the right to refuse medical treatment. The fundamental problem, in this respect, is how to make sure that the will of the patient is respected when the circumstances do not allow him/her to indicate his/her preferences. Who is entitled, in such cases, to make the decision to discontinue treatment? Should end-of-life decisions be linked to the existence of a clear, undisputable will expressed by the patient prior his/her conditions worsened? Or should they be based on a so-called "substituted judgment" by a relative or guardian of the patient? The book shows how views and legal provisions differ widely across countries.

The relationship between euthanasia and palliative care is another focal point in the book. Whereas the two practices are extremely distant in theory (the first being about ending life, the second about improving the quality of life), experience across countries shows that these two concepts tend to converge and mix when it comes to end-of-life decision-making.

Finally, the book analyzes the legal and jurisprudential aspects of euthanasia in different countries. The authors point out¹² that Japan and The Netherlands (and

¹² EUTHANASIA IN INTERNATIONAL AND COMPARATIVE PERSPECTIVE, *supra* note 5, at 17.

Belgium, RCA) allow for a greater and more active role of the citizen in end-of-life matters. Procedural issues—such as discretion of prosecution and the collection of information on euthanasia cases—are also discussed and analyzed.

My Review is divided into five parts. First, I outline the book's strengths. I proceed by speaking of the need for clear and cohesive terminology. I then discuss end-of-life decision-making in some of the countries: Belgium, The Netherlands, and the State of Oregon in the United States, all allow PAS. Belgium and The Netherlands also allow euthanasia. I also discuss Israel's Dying Patient Law,¹³ enacted by the Knesset on December 5, 2005. Finally, I make some suggestions for improvement, including a detailed proposal for PAS which I conceive to be the best policy when balancing one against the other the autonomy of the patient, on the one hand, and the safeguards against abuse when life might be considered too lightly, on the other. Indeed, the main difference between euthanasia and PAS is that in euthanasia, it is the physician who makes the final act of taking patient's life, whereas in PAS it is the patient who takes his or her life. In euthanasia, the physician has control over the process. In PAS, the physician controls the procedure up until the last act. The patient has control over the very act of suicide.

II. *The Book's Strengths*

The book is the result of the International Academy of Comparative Law Congress which was held in Utrecht in July 2006. It provides very useful information about the legal situation in fourteen countries, and how they struggle with end-of-life concerns. As far as I can judge, the scholars present middle-of-the-road analysis of the respective situation in their countries. Thus the reader receives a good depiction of the different end-of-life jurisdictions in each country as reflected by the consensus in that same country. The book will thus be useful to lawyers and bioethicists who wish to gain insights into the penal codes of fourteen countries, designed to address the tension between sanctity of life and quality of life.

The overwhelming majority of the national reports indicate that the penal codes do not contain a formal definition of euthanasia. Euthanasia is not allowed. In many

¹³ Dying Patient Law, 2005, S.H. 58.

of the countries assisted suicide is provided for as a separate crime in the Penal Code. This is the case in Belgium, Croatia, Italy, Japan, The Netherlands and most parts of the United States.

Although the bulk of the book does not address active euthanasia (the intentional ending of a patient's life by lethal injection) directly, as active euthanasia is illegal in most countries covered in it, *Euthanasia in International and Comparative Perspective* provides a wealth of information about end-of-life concerns: the relevant criminal codes and case law of each country are outlined; the law and practice of passive euthanasia (withholding or withdrawing of life-sustaining treatment) is outlined. The reader can find information regarding the euthanasia debate in Germany; advance directives in Belgium, The Netherlands, Germany, Israel, and Italy; refusal of treatment in Belgium, The Netherlands, Israel, and the United States; palliative care in Belgium, The Netherlands and Spain; palliative sedation which involves the administration of deep sleep-inducing medication to patients who have at most two weeks to live in Croatia and The Netherlands; withdrawal of treatment by physicians and non-physicians in Croatia; terminal care in Finland; Persistent Vegetative State (PVS) patients in Germany and the United States; the provision of nutrition and hydration in the United States; rights of incompetent patients in Israel and the United States; informed consent in Israel; treatment and non-treatment of severely-ill newborns in The Netherlands; euthanasia tourism,¹⁴ and analysis of a leading precedent of the European Court of Human Rights (*Pretty v. the United Kingdom*).¹⁵

III. Terminology

People are social beings. We communicate with one another, converse, exchange ideas and different points of view via language/s and signs. Language constructs affects and changes reality, facilitating communication, promoting understanding, helping to erect bridges between cultures. In the field of medical ethics, concepts and categories should convey a clear meaning, and should not be opened for interpretation. Because phenomenology is important—language does play a critical

¹⁴ EUTHANASIA IN INTERNATIONAL AND COMPARATIVE PERSPECTIVE, *supra* note 5, at 124.

¹⁵ *Pretty v. United Kingdom*, 2002-III Eur. Ct. H.R. 155, 185; *see also* EUTHANASIA IN INTERNATIONAL AND COMPARATIVE PERSPECTIVE, *supra* note 5, at 86-89.

role in the shaping and reshaping of our existence—it is important to reflect on the language people use to describe their experiences, especially those concerning life and death.¹⁶ Thus, to title most of the chapters “Euthanasia in ... “only to find that euthanasia, in the active sense of the term, does not exist in that country is odd. For instance, the chapter “Euthanasia in Croatia” starts with the following statement: “Euthanasia is not recognized as a legal term in Croatia.”¹⁷ “Euthanasia in Germany” explains that “The internationally recognized term ‘euthanasia’ is rarely applied in Germany due to the euthanasia programmes carried out during the national socialist era and the consequent discredit brought with this.”¹⁸ In Israel, active euthanasia is explicitly prohibited.¹⁹ The chapter “Euthanasia in Italy” opens with: “There is no definition of ‘euthanasia’ in the Italian legal system, nor is there any specific statutory provision in this field.”²⁰ “Euthanasia in Finland” explains “Euthanasia, as a concept, does not feature in Finnish legislation.”²¹ The chapter “Euthanasia in Japanese Law” states in the beginning: “In Japan, there are no acts, specific provisions or official guideline on euthanasia,” maintaining that “an official definition of euthanasia does not exist, due to the absence of statutes, regulations and official guidelines on euthanasia.”²² “Euthanasia in Poland” opens with saying: “The notion of euthanasia has not been defined in Polish statutory law.”²³ In most countries under study, there is no euthanasia law, and apart from the opening chapter where some comparisons are drawn between the legal situations, no comparative analysis is offered throughout the book. The question, then, begs: Why title the book *Euthanasia in International and Comparative Perspective*? More correctly and appropriately was to title the book *End-of-Life Considerations in International and Comparative Perspective*, or even more accurately *End-of-Life Considerations in Fourteen Jurisdictions*.

Some of the countries reported in the book adopted forms of *passive* euthanasia. Passive euthanasia (also termed “forgoing life-sustaining treatment”) may take two forms: one is abstention from performing acts that prolong the patient’s life. An example may be refraining from connecting a patient to a respirator or to a resuscitation

¹⁶ See Raphael Cohen-Almagor, *Language and Reality at the End of Life*, 28 J. L. MEDICINE & ETHICS 267 (Fall 2000).

¹⁷ EUTHANASIA IN INTERNATIONAL AND COMPARATIVE PERSPECTIVE, *supra* note 5, at 55.

¹⁸ *Id.* at 108.

¹⁹ *Id.* at 161.

²⁰ *Id.* at 167.

²¹ *Id.* at 74.

²² *Id.* at 187.

²³ *Id.* at 227.

machine. The other form involves discontinuation of actions designed to sustain life. This means withdrawing machines to which the patient has already been connected.²⁴ In Croatia, passive euthanasia is exempt from liability unless there is an affirmative duty for perpetrator to intervene and render aid or treatment, or unless perpetrator is duty-bound to keep the patient alive.²⁵ In Germany, the focus of current deliberations on criminal law reform is on the implementation of the patient's right to refuse medical treatment and on the question whether additional objective reasons exist, irrespective of the patient's will, to limit life-sustaining measures.²⁶ In Greece, the right to refuse treatment was first introduced through the ratification of the *European Convention on Human Rights and Biomedicine* (Law no. 2619/1998) and it is also enshrined in the Greek Code on Ethics and Medical Conduct, approved by parliament in November 2005, which expressly provides that a physician is bound to refrain from any action for which the patient's prior consent has not been received.²⁷ Israel's Dying Patient Law provides for withholding and withdrawing of treatment from patients who suffer from incurable disease and it is estimated that they will die within the next six months (see discussion below).

The book is edited by two Dutch scholars from Tilburg University, thus my initial expectation was that they would adopt the Dutch stance on terminology. The Dutch pride themselves for their clarity, precision, and sincerity. Unlike other countries that distinguish between active and passive euthanasia, between direct (lethal injection aims at ending life) and indirect euthanasia (life is shortened by other means, i.e., disconnecting a patient from a respirator or providing sedative strong medication that could result in death), and between voluntary and involuntary euthanasia, the Dutch definition of the term is exact: the intentional taking of someone's life at his or his/her explicit request. According to the law, only a competent patient's request can be accepted. Consequently:

- a. What is termed "euthanasia" in The Netherlands is called "active euthanasia" in other parts of the world. In the Dutch conception, euthanasia is active by definition and there is no need to specify the act by the term "active," as other countries do. I regard this conception as straightforward and wise.

²⁴ Cf. James Rachels, *Killing and Letting People Die of Starvation*, 54 *PHILOSOPHY* 159 (Apr. 1979).

²⁵ EUTHANASIA IN INTERNATIONAL AND COMPARATIVE PERSPECTIVE, *supra* note 5, at 62.

²⁶ *Id.* at 120.

²⁷ *Id.* at 134.

- b. All other kinds of end-of-life (“terminal”) care bear other names. Thus, for instance, withdrawal of treatment is not considered euthanasia. In The Netherlands, this term is deemed illogical and useless insofar as passive euthanasia is self-contradictory because it concerns the omission of a treatment to which the patient has not consented.²⁸ The prevailing Dutch perspective regards any treatment that has no clear medical benefit for the patient as futile. The argument is that no patient should be subjected to useless medical interventions, or that these treatments should be offered as an option to patients.²⁹

The need for a clear and unified terminology in order to promote understanding between states and culture is urgent and quite apparent from reading the national reports. In Greece, a distinction is made between “direct active euthanasia” and “indirect active euthanasia.” The former occurs when “the patient is terminated by drastic means; the latter when the medication administered primarily aims at the amelioration of the dying patient’s quality of life, hastening death only as a side effect.”³⁰ Similarly, in Italy they use the term “indirect” euthanasia.³¹ In other countries, the latter does not qualify as “active euthanasia.” The common parlance is “double effect.” In the absence of law authorizing physician to shorten life when necessary, in many countries physicians resort to the double effect doctrine.

The ethical concept of double effect is used to justify medical treatment with positive and negative consequences: the relief of suffering but it might be the case that death is an unintended consequence. It comes from “the double effect” doctrine developed by Roman Catholic moral theologians in the Middle Ages as a response to situations requiring actions in which it is impossible to avoid all harmful consequences. The doctrine makes intention in the mind of the doctor a crucial factor in judging the moral correctness of the doctor’s action because of the Roman Catholic teaching that it is never permissible to “intend” the death of an “innocent person.” An innocent person is one who has not forfeited the right to life by the way he/she behaves, e.g., by threatening or taking the lives of others.³²

²⁸ G.K. Kimsma & E. van Leeuwen, *Dutch Euthanasia: Background, Practice, and Present Justifications*, 2 CAMBRIDGE Q. HEALTHCARE ETHICS 24 (1993).

²⁹ RAPHAEL COHEN-ALMAGOR, EUTHANASIA IN THE NETHERLANDS: THE POLICY AND PRACTICE OF MERCY KILLING ch. 1 (2004).

³⁰ EUTHANASIA IN INTERNATIONAL AND COMPARATIVE PERSPECTIVE, *supra* note 5, at 132.

³¹ *Id.* at 171.

³² Joseph M. Boyle Jr., *Toward Understanding the Principle of Double Effect* 90 ETHICS 527 (July 1980); Joseph M. Boyle Jr., *Who Is Entitled to Double Effect?*, 16 J. MEDICINE & PHILOSOPHY 475

The double effect doctrine is based on two basic presuppositions: (1) the doctor's motivation is to alleviate suffering; (2) the treatment must be proportional to the illness.³³ The doctrine applies if the desired outcome is judged to be "good" (e.g. relief of suffering); the "bad" outcome (e.g. death of patient) is not intended; the "good" outcome is not achieved by means of the "bad," and the "good" outcome outweighs the "bad." I am not principally opposed to the double effect doctrine as I understand that in the absence of relevant laws physicians need some sort of formula to address the legal lacuna and help patients to the best of their professional conscience. My lack of opposition stems from practical, rather than ethical, considerations.³⁴ I think it is a different terminology and also a practical way—not always sincere—to deal with a pressing problem in countries that prohibit PAS and euthanasia. Religious authorities speak of double effect and practical doctors use it in their practice as this is the only option they have to shorten lives of suffering. This doctrine serves both spiritual leaders and careful healers as a way out of dealing directly and sincerely with the question of mercy killings and PAS. Undoubtedly the doctrine provides a better solution than letting people die slowly in terrible agony. Doctors prescribe large doses of medication knowing that, as a result, the suffering will be lessened and also that life would be shortened. They feel comfortable with what they are doing: they are not breaking the law; they are acting in accordance with their medical understanding and providing solace to suffering patients.

(1991); CHARLES F. MCKHANN, A TIME TO DIE: THE PLACE FOR PHYSICIAN ASSISTANCE 102-06 (1999); Timothy E. Quill, Rebecca Dresser & Dan W. Brock, *The Rule of Double Effect—A Critique of Its Role in End-of-Life Decision Making*, 337 NEW ENG. J. MEDICINE 1768-71. (Dec. 11, 1997). See also the correspondence on the rule of double effect in 338 NEW ENG. J. MEDICINE 1389-90 (May 7, 1998). For further discussion on Thomas Aquinas and double effect, see *Doctrine of Double Effect*, STANFORD ENCYCLOPEDIA OF PHILOSOPHY (2004), at <http://plato.stanford.edu/entries/double-effect>.

³³ Boyle, *Toward Understanding the Principle of Double Effect*, *supra* note 32 and *Who Is Entitled to Double Effect?*, *supra* note 32. See also the June 24, 1999 testimony of Dr. Walter R. Hunter before the Committee on the Judiciary, available at <http://www.house.gov/judiciary/hunt0624.htm>; F.M. Kamm, *Physician-Assisted Suicide, the Doctrine of Double Effect, and the Ground of Value*, 109 ETHICS 586-91 (1999).

³⁴ Cf. *When Doctors Might Kill Their Patients*, 318 BMJ 1431-32 (May 29, 1999); T.E. Quill, R. Dresser & D.W. Brock, *The Rule of Double Effect—A Critique of Its Role in End-of-Life Decision Making*, 337 NEW ENG. J. MEDICINE 1768 (Dec. 11, 1997); <http://plato.stanford.edu/entries/double-effect>.

IV. *Countries Surveyed*

A. *Belgium*

One of the book's strengths is that it presents a middle-of-the-road view of end-of-life legislation in each country. That, however, means that the analysis often lacks a critical eye. The authors of the Belgian national report criticize the euthanasia law because of its *narrow* scope of application, meaning they would have liked to expand the law so it would relate to other end of life decisions, like the application of opioids to alleviate pain which might result in life-shortening (double effect) and the withholding or withdrawing of life-prolonging treatment (passive euthanasia).³⁵ I would like to voice other concerns which, to my mind, are exceedingly more important.

The major concern relates to the number of people who are killed without expressing request. In 1998 Deliens and colleagues estimated that 705 patients (1.3% of all deaths) died from euthanasia or PAS, and that in 1796 cases (3.2 or 3.8%) lethal drugs were administered without the explicit request of the patient.³⁶ Life ending without request was more common than euthanasia. In 2001, 1.5% of death cases involved ending life without the patient's request. Thus fear of abuse is certainly relevant.

One way to address this issue is to advance PAS for all patients who are able to swallow oral medication. On the other hand, administration of lethal drugs means physicians taking responsibility. Consequently, in Belgium there are relatively few cases of PAS. I suggest putting this issue on public agenda, speaking openly about the findings and the fear of abuse, and suggest PAS as an alternative to euthanasia.

A related concern is the practice of terminal sedation. In administering terminal sedation, patients who are dying are given sedation that keeps them in a state of unconsciousness until death. In contrast to euthanasia, terminal sedation is not aimed at ending a patient's life but the administering of drugs is often part of palliative care to combat pain, fear and distress. It is not "slow euthanasia" because euthanasia

³⁵ Walter De Bondt & Thierry Vansweevel, *Euthanasia in Belgium*, in EUTHANASIA IN INTERNATIONAL AND COMPARATIVE PERSPECTIVE, *supra* note 5, at 31-32.

³⁶ Luc Deliens, Freddy Mortier, Johan Bilsen et al., *End-of-life Decisions in Medical Practice in Flanders, Belgium: A Nationwide Survey*, 356 LANCET 1806-11 (Nov. 25, 2000).

requires the consent of the patient, while terminal sedation does not require such consent. Here the fear of abuse is great. It is estimated that 8% of all death cases in 2001 were cases of terminal sedation, about 4,500 cases in Flanders alone.³⁷ There is no knowledge whether the patient's consent was sought or given. At present the Belgian physicians do not have any directives on this. There is no legal regulation, no public or professional scrutiny to examine to what extent the procedure is careful, and there is no knowledge whether consultation was provided. This situation calls for a change. There should be clear guidelines when it is appropriate, if at all, to resort to this practice.

Section 3 of the Belgium law holds that the euthanasia request should be voluntary, well-thought-out, and reiterated, and should not be the result of outside pressure.³⁸ Indeed, it must be ensured that the patient's decision is not a result of familial and environmental pressures. 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 and is not addressed in the book is whether physicians should highlight the option of euthanasia to their patients. One thing is to review all possible options, and quite another is to focus on euthanasia. Presently euthanasia can be put forward by doctors. They may initiate the discussion about euthanasia and concentrate the focus on the practice. This was one of my concerns when I did my independent study in Belgium and The Netherlands. Physicians seemed oblivious that the voluntariness of the process may be compromised by stressing the option of euthanasia. 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.³⁹ Often time,

³⁷ Johan Bilsen, Robert Vander Stichele, Bert Broeckaert, et al., *Changes in Medical End-of-Life Practices during the Legalization Process of Euthanasia in Belgium*, 65 *SOC. SCIENCE & MEDICINE* 803-08 (2007).

³⁸ Section 3 of the Belgian Euthanasia Law, available at <http://www.kuleuven.ac.be/cbmer/viewpic.php?LAN=E&TABLE=DOCS&ID=23>.

³⁹ F. Mortier, J. Bilsen, R.H. Vander Stichele, et al., *Attitudes, Sociodemographic Characteristics, and Actual End-of-Life Decisions of Physicians in Flanders, Belgium*, 23 *MEDICAL DECISION MAKING* 502-10 (Nov.-Dec. 2003).

when the physicians approve of euthanasia, their patients opt for euthanasia. And when physicians oppose the practice and prefer other end-of-life practices, their patients make decisions in line with what their physicians offer. Evidently physicians have great influence over their patients.

The physician's role is commonly understood as a healing role.⁴⁰ With respect to professional ethics, talking about euthanasia upon a patient's request is different from accentuating 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, *mercy* killing. 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 which is in accordance with the principles of beneficence and patient's autonomy. But when euthanasia is highlighted, this might undermine the patient's voluntary wishes.

Thus it is argued that physicians' suggestions constitute powerful influence on the patients' choices of treatment. The patients' choices may reflect their physicians' attitude. The patient, who trusts the long-time general practitioner, might feel that he is being condemned to death and that he is wasting the doctor's time. Putting emphasis on euthanasia might undermine the patient's 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.

The role of the physician is not to push patients to choose euthanasia. Today in Belgium it is hard to argue that patients are unaware of the option. 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 idea that the patient wishes to live despite his/her severe illness and medical condition. The physician should consider the consequences of the way they frame the discussion on the patient's condition; on the patient's loved ones; and on the doctor-patient relationship built on trust over

⁴⁰ See J.R. Peteet, *Treating Patients Who Request Assisted Suicide. A Closer Look at the Physician's Role*, 3 ARCH FAMILY MEDICINE 723-27 (Aug. 1994); E. Rosenthal, *When A Physician Is Asked, 'Help Me Die'*, N.Y. TIMES, Mar. 13, 1997, at A1, B4.

the years. In a matter of life and death, caution is not only recommended: It is a must.

The euthanasia law necessitates discussing the availability and consequences of palliative care with the patient. In 2007 Belgium was ranked third of 52 countries in palliative care resources after Iceland and the UK.⁴¹ It is the physician's duty to inform the patient of palliative treatment.⁴² Most worrisome is to know that sometime when physicians administered life-shortening drugs in order to alleviate pain, they did not consult palliative care specialist. Indeed, in at least four recorded cases they did not consult any other health care personnel.⁴³

Section 3 of the law 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 his/her life.⁴⁴

Another cause for concern is physicians' attitude to euthanizing newborns. A 2005 survey of Flanders doctors revealed three quarters 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 by how much time they estimated life was shortened.⁴⁵ The response rate was 87%; 254 questionnaires were returned. End-of-life decisions were possible for 194 deaths. In 143 cases over the course of a year, a medical decision preceded death. The majority involved withdrawing or withholding treatment. In 17 deaths high doses of painkillers were explicitly administered to end the newborn's life. To recall: administering lethal drugs to minors is against the law. Still, of 121 doctors questioned, 79% thought it was their "professional duty," if necessary, to prevent unnecessary suffering by hastening death.

⁴¹ Jan L Bernheim, Reginald Deschepper, Wim Distelmans, Arsène Mullie, Johan Bilsen, *Development of Palliative Care and Legalisation of Euthanasia: Antagonism or Synergy?*, 336 *BMJ* 864 (Apr. 19, 2008); Editor, *In Belgium, Euthanasia and Palliative Care Work Together*, *MEDICAL NEWS TODAY*, Apr. 18, 2008, available at <http://www.medicalnewstoday.com/articles/104629.php>.

⁴² EUTHANASIA IN INTERNATIONAL AND COMPARATIVE PERSPECTIVE, *supra* note 5, at 45.

⁴³ Veerle Provoost, Filip Cools, Johan Bilsen, et al., *The Use of Drugs with a Life-shortening Effect in End-of-life Care in Neonates and Infants*, 32 *INTENSIVE CARE MEDICINE* 136 (2006).

⁴⁴ 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).

⁴⁵ Veerle Provoost, Filip Cools, Freddy Mortier, et al., *Medical End-of-Life Decisions in Neonates and Infants in Flanders*, 365 *THE LANCET* 1315-16 (Apr. 9, 2005).

The vast majority (88%) also accepted quality-of-life ethics: 58% supported the legal termination of life in some cases.⁴⁶ In the actual practice, in most cases (84%) of the cases the decision was made in consultation with the parents. Still, in 22 deaths parents were not consulted. (In 17 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).⁴⁷ Belgium should invest more thinking and attention to prevent abuse and unnecessary death.

B. *The Netherlands*

The authors of this national report state at the outset that they aim “to provide some objective facts about the policies which are currently pursued in our country,”⁴⁸ and that this “will enable the reader to make up his own mind as to the merits and demerits of the situation at hand.”⁴⁹ They maintain that the debates on euthanasia aimed to achieve three objectives: to assure a careful decision-making process, to promote transparency, and to increase accountability.⁵⁰ The authors describe the main components of the law, and then discuss some of the leading case law. The discussion tends to be descriptive, not critical. Meager critique was expressed regarding the fact that a substantial number of physicians refused to comply with the procedure that obliges them to report cases of euthanasia. The authors write: “many of the cases that manifestly need no scrutiny are actually being reported, while those instances where euthanasia has been performed in a substandard way are likely to be heavily underreported.”⁵¹ The authors dismiss the critique against the Groningen Protocol on

⁴⁶ *Id.* at 1319. See also *Doctors ‘Would Help Babies to Die,’* THE EVENING STANDARD, circulated by right_to_die_2@mailman.efn.org on Apr. 8, 2005; *Baby euthanasia is a reality,* EXPATICA REPORT, Apr. 11, 2007.

⁴⁷ Veerle Provoost, Filip Cools, Peter Deconinck, et. al., *Consultation of Parents in Actual End-of-life Decision-making in Neonates and Infants*, 165 EUR. J. PEDIATR. 859-66 (Dec. 2006). See also V. Provoost, L. Deliens, F. Cools, et al., *A Classification of End-of-life Decisions in Neonates and Infants*, 93 ACTA PAEDIATRICA 1-5 (2004). For critical reading, see Chris Feudtner, *Control of Suffering on the Slippery Slope of Care*, 365 THE LANCET 1284-86 (Apr. 9, 2005).

⁴⁸ EUTHANASIA IN INTERNATIONAL AND COMPARATIVE PERSPECTIVE, *supra* note 5, at 195.

⁴⁹ *Id.*

⁵⁰ *Id.* at 197.

⁵¹ *Id.* at 212.

terminating the lives of severely-ill newborns, regretting that the critique is confused due to “lack of knowledge.”⁵² They mention only in passing the most worrisome data that 0.7% of all deaths in the Netherlands concern patients who were put to death without making an explicit request.⁵³ In their opinion, the very first drawback of the Dutch policy and practice of euthanasia is that “the Dutch are quite vulnerable to attacks on their policies, based on misconceptions. Many criticisms have been directed to the model, resting on assumptions that are clearly and demonstrably false.”⁵⁴ They maintain that some of the criticisms are caused by “misinformation spread by Dutch people opposing their own government’s philosophy.”⁵⁵

The Netherlands has the longest experience practicing euthanasia and it has attracted national and international criticisms for its policy and practice. Euthanasia has been practiced there since the early 1970s. I have been studying Dutch euthanasia since 1994. Prior to my first field research trip to The Netherlands I supported euthanasia and published a few articles endorsing the practice.⁵⁶ After close examination of the practice, I no longer support euthanasia. It is not that I stopped believing in the *moral* justification of euthanasia. Morally speaking, I can think of cases in which euthanasia can be justified. However, there is a fine line between a moral idea and transforming it into practice, between theory and application. Witnessing the amount of abuse in the Netherlands, where people are killed prematurely, I can no longer condone the practice.⁵⁷

The Dutch policy does not work because *all* of the Dutch legal guidelines for euthanasia, without exception, are broken time and time again. It is not always the

⁵² *Id.* at 217. For further discussion, see Jim Holt, *Euthanasia for Babies?*, N.Y. TIMES, July 10, 2005; Tony Sheldon, *Killing or Caring?*, 330 BMJ, Mar. 12, 2005, at 560; available at <http://forums.canadiancontent.net/news/35311-new-mercy-killing-rules-netherlands.html>. The Groningen Protocol was introduced in the Dutch legislation in 2005, requiring that before euthanasia is performed, the child’s parents and a team of physicians and social workers agree on the futility of further treatment. A waiting period of several days is required in which parents can think over the decision and say goodbye to their child. See Eduard Verhagen & Pieter J.J. Sauer, *The Groningen Protocol—Euthanasia in Severely Ill Newborns*, 352 NEW. ENG. J. MEDICINE 959-62 (Mar. 10, 2005).

⁵³ EUTHANASIA IN INTERNATIONAL AND COMPARATIVE PERSPECTIVE, *supra* note 5, at 220.

⁵⁴ *Id.* at 223.

⁵⁵ *Id.*

⁵⁶ See, e.g., Raphael Cohen-Almagor, *Reflections on the Intriguing Issue of the Right to Die in Dignity*, 29 ISR. L. REV. 677-701 (1995) and *Autonomy, Life as an Intrinsic Value, and Death with Dignity*, 1 SCIENCE AND ENGINEERING ETHICS 261-72 (1995).

⁵⁷ For an elaborated discussion, see COHEN-ALMAGOR, EUTHANASIA IN THE NETHERLANDS, *supra* note 29.

patient who makes the request for euthanasia or PAS. Often the doctor proposes euthanasia to the patient. Sometimes the family initiates the request. The requirement that the request be voluntary is thus compromised. On occasion, the patient's request is not well considered. There have been cases in which no request was made and patients were put to death. Furthermore, the patient's request is not always durable and persistent as required.⁵⁸

The law speaks of "unbearable suffering," a term that evokes criticism because it is open to interpretation.⁵⁹ Are dementia patients, for instance, suffering unbearably? Apparently not, yet there were a few euthanasia cases of demented patients.⁶⁰ The law instructs that a doctor must perform the euthanasia. Yet, there were cases in which nurses had administered the procedure. It was estimated that 10% of the nursing home physicians let the nurse or even the patient's family members administer the euthanasia drug.⁶¹ Another key legal guideline requires that before the doctor assists the patient, a second doctor must be consulted. This requirement has been breached many times.⁶² It is instructed that the patient's general practitioner performs euthanasia, yet on occasion the consultant conducted the final act. The doctor must keep a full written record of every case and report it to the prosecutorial authorities as a case of euthanasia or PAS, and not as a case of death by natural causes. This requisite has also been violated frequently.⁶³ Notwithstanding, many of my Dutch interviewees were quite content with the law. One cannot expect a policy that would work 100%

⁵⁸ *Id.*

⁵⁹ For deliberation on the range of what "unbearable suffering" means, see CARLOS F. GOMEZ, *REGULATING DEATH* 99-104 (1991).

⁶⁰ For further discussion, see Anne-Mei The, Roeline Pasman, Bregje D. Onwuteaka-Philipsen, et al., *Withholding the Artificial Administration of Fluids and Food from Elderly Patients with Dementia: Ethnographic Study*, 325 *BMJ* 1326 (Dec. 7, 2002).

⁶¹ MARTIEN TOM MULLER, *DEATH ON REQUEST* 52 (1996).

⁶² John Keown, *The Law and Practice of Euthanasia in the Netherlands*, 108 *THE L. Q. REV.* (Jan. 1992); HERBERT HENDIN, *SEDUCED BY DEATH* (1997); BREGJE DORIE ONWUTEAKA-PHILIPSEN, *CONSULTATION OF ANOTHER PHYSICIAN IN CASES OF EUTHANASIA AND PHYSICIAN-ASSISTED SUICIDE* (1999); Bregje D. Onwuteaka-Philipsen, Gerrit van der Wal, Piet J. Kostense & Paul J. van der Maas, *Consultants in Cases of Intended Euthanasia or Assisted Suicide in the Netherlands*, 170 *MJA* 360-63 (1999); G. van der Wal, J. Th. M. van Eijk, H.J.J. Leenen & C. Spreeuwenberg, *Euthanasia and Assisted Suicide. II. Do Dutch Family Doctors Act Prudently?*, 9 *FAMILY PRACTICE* (1992); Breje D. Onwuteaka-Philipsen, Gerrit van der Wal, Piet J. Kostense & Paul J. van der Maas, *Consultation with Another Physician on Euthanasia and Assisted Suicide in the Netherlands*, 51 *SOCIAL SCIENCE AND MEDICINE* (2000).

⁶³ For deliberation, see Jacqueline M. Cuperus-Bosma, Gerrit van der Wal and Paul J. van der Maas, *Physician-assisted Death: Policy-making by the Assembly of Prosecutors General in the Netherlands*, 4 *EUR. J. HEALTH L.* 225-238 (1997).

of the time, but given the many frequent breaches of all the legal guidelines, the Dutch should invest effort to find remedies and to prevent abuse and lawlessness.

I was not surprised to read the relaxed tone of the two Dutch scholars who wrote the Dutch national report. During my frequent visits to The Netherlands I heard time and again rosy pictures about their euthanasia system.⁶⁴ The vast unanimity of opinion might suggest that there is not enough reflective thinking about this issue, that the practice of euthanasia is taken for granted. Unfortunately, there might be greater room for abuse in such an environment of trust and lack of critical questioning. Even issues that are acknowledged as problems are not conceived to be serious enough to press.⁶⁵ The Dutch tend to accept highly troublesome contentions and to consider and allow euthanasia in cases where the law is severely breached and to condone killing when patients did not ask to end their lives. The culture around euthanasia makes the practice accessible within the confines of what is permissible with little public critique. This culture, however, has a chilling effect upon open, critical debate.⁶⁶

Some troubling questions have arisen as a result of my thirteen years of study of the Dutch euthanasia situation. The high number of unreported cases of euthanasia is alarming. The fact that some patients have been put to death without prior consent is extremely worrisome. Society has to ensure that no abuse takes place and that the existing legal procedure does not open a window for abuse or provide a way to get rid of “unwanted” patients. More research should be done on what is termed outside of The Netherlands “passive euthanasia,” that is, the withholding or withdrawal of treatment and also on the practice of terminal sedation. Unlike euthanasia, terminal sedation does not need to be reported to authorities. A 2003 study asked 410 Dutch doctors whether they used terminal sedation and why. The answers indicated that 52% had applied on occasion terminal sedation and in a large majority of these cases, the sedation was administered partly to hasten a patient’s death. Dutch doctors administer terminal sedation in four to 10% of patient deaths.⁶⁷ A more recent study shows that

⁶⁴ See COHEN-ALMAGOR, EUTHANASIA IN THE NETHERLANDS, *supra* note 29.

⁶⁵ Raphael Cohen-Almagor, *The Guidelines for Euthanasia in The Netherlands: Reflections on Dutch Perspectives*, 9 ETHICAL PERSPECTIVES 3-20 (2002).

⁶⁶ Hendin reached a similar conclusion. Cf. HERBERT HENDIN, *SEDUCED BY DEATH* 100 (1997). See also Raphael Cohen-Almagor, ‘Culture of Death’ in *The Netherlands: Dutch Perspectives*, 17 ISSUES IN L. & MED. 167-79 (Fall 2001).

⁶⁷ Judith A.C. Rietjens, et al., *Terminal Sedation in The Netherlands*, 141 ANNALS OF INTERNAL MED. 966-67 (Dec. 21, 2004); Judith A. C. Rietjens, et al., *Terminal Sedation and Euthanasia*, 749-53 166 ARCH INTERN (2006).

terminal sedation is on the rise. It found that 1,800 people—7.1% of all deaths in the Netherlands in 2005—was drugged into continuous deep sedation shortly before dying.⁶⁸ To prevent potential abuse, special attention should be given to demented patients, newborns, and children. The law needs to be clarified in detail, closing the door to possible misinterpretation that could lead to ill-treatment.⁶⁹

Euthanasia should not be regarded as an integral part of normal medical care. The fact that many Dutch physicians do not wish to be bothered with the procedures is alarming. It shows that they have not internalized the concept that euthanasia is an exceptional medical procedure and, as such, requires social control. The book does little in addressing this important concern. It is possible that the moral ambiguity that surrounded the issue for many years—allowing the practice while it was still prohibited under the Penal Code—made doctors feel that they had better conduct euthanasia in private, keeping it only between the patients, their families, and themselves. Wherever euthanasia is practiced, it should be subject to constructive criticism. It is preferable to draft a better legal framework. In the event that we see that the new euthanasia policy does not improve the situation, then yet again we should pursue a public debate in which different sectors of society can take part. The understanding of euthanasia and its importance should be changed for it to work properly without abusing the rules of caution.

The last evaluation of euthanasia legislation that was presented to the Dutch State secretary for public health Jet Bussemaker in May 2007 showed that the number of euthanasia cases has dropped over the past few years, part of the reason being that physicians opt more for terminal sedation. In 2005, 1.7% of all deaths in the Netherlands (2,297 people) were the result of euthanasia, more than a third less than the 3,500 cases in 2001. One hundred and thirteen patients died as a result of PAS. In both 2005 and 2001, the highest rates of euthanasia or PAS were found for patients aged 64 years or younger, for men, and for patients with cancer. Furthermore, most

⁶⁸ Derek Humphrey, *Terminal Sedation in Holland More Used than Euthanasia*, (May 21, 2008), available at <http://assistedsuicide.org/blog/2008/03/21/terminal-sedation-in-holland-more-used-than-euthanasia>.

⁶⁹ Astrid M. Vrakking, Agnes van der Heide, Veerle Provoost, et al., *End-of-life Decision Making in Neonates and Infants: Comparison of The Netherlands and Belgium (Flanders)*, 96 *ACTA PAEDIATRICA* 820-24 (2007). For further discussion, see Astrid M. Vrakking, Agnes van der Heide, Bregje D. Onwuteaka-Philipsen et al., *Medical End-of-Life Decisions Made for Neonates and Infants in The Netherlands, 1995-2001*, 365 *THE LANCET* 1329-31 (Apr. 9, 2005).

acts of euthanasia or assisted suicide were carried out by general practitioners.⁷⁰

Additionally, 0.4% deaths were the result of the use of lethal drugs not at the explicit request of the patient;⁷¹ this percentage was not significantly different from those in previous years. When life was ended without the explicit request of the patient, there had been discussion about the act or a previous wish of the patient for the act in 60.0% of patients, as compared with 26.5% in 2001. In 2005, the ending of life was not discussed with patients because they were unconscious (10.4%) or incompetent owing to young age (14.4%) or because of other factors (15.3%). Of all cases of the ending of life in 2005 without an explicit request by the patient, 80.9% had been discussed with relatives. In 65.3% of cases, the physician had discussed the decision with one or more colleagues.⁷²

As could have been expected, the number of patients suffering from incurable disease receiving palliative sedation has increased. There was a substantive increase in the use of palliative sedation in the same period from 8,500 to 9,600.⁷³ The number of physician-assisted suicides also decreased, from 300 in 2001 to 100 in 2005. There were also fewer patient requests for euthanasia or suicide assistance: 8,400, compared to 9,700 in 2001.⁷⁴

The good news concerns the issue of reporting. Doctors are required to report euthanasia cases to a regional review committee which monitors that all conditions have been met. The evaluation indicates that more and more doctors are honouring this reporting requirement. While only 18 % reported euthanasia cases in 1990, 54 in 2001, 80% did so in 2005.⁷⁵ There is a steady increase in the reporting rate although the Dutch interest is to reach full level of reporting.

⁷⁰ Agnes van der Heide, Bregje D. Onwuteaka-Philipsen et al., *End of Life Practices in the Netherlands under the Euthanasia Act*, 356 NEW ENG. J. MEDICINE 1957-65 (May 10, 2007).

⁷¹ *Id.*

⁷² *Id.*

⁷³ *Id.*; *Number of Euthanasia Cases Drops*, EXPATICA REPORT (May 10, 2007), circulated by org.opn.lists.right-to-die@lists.opn.org.

⁷⁴ *Id.*

⁷⁵ *Id.* See also 33 MAGAZINE OF RIGHT TO DIE-NL (NVVE) (June 2007); Timothy E. Quill, *Physician Assisted Death in Vulnerable Populations*, 335 BMJ 625-26 (Sept. 2007).

C. Israel

The report on Israel begins with a discussion on the Basic Law: Human Dignity and Liberty (1992);⁷⁶ it then discusses the Penal Law,⁷⁷ the Patients' Right Law (1996)⁷⁸ and some leading precedents pertaining to end-of-life. The report concludes with the Dying Patient Law (2005) which rightly stands in the focus of discussion.

I should say in the outset that I was a member of the public committee established to draft the Dying Patient Law. I will take this opportunity to provide behind-the-scene insights into some of the issues raised by the report's authors.

The Dying Patient Committee was convened in early 2000 by Professor Avraham Steinberg upon the request of the then Minister of Health Shlomo Benizri of the Ultra-Orthodox Shas Party. There were quite a few appeals to the courts by patients who wished to withhold or withdraw treatment, and Minister Benizri felt that it was time to settle the issue through law. This initiative was welcomed by Steinberg as well as by Israeli experts. Fifty eight experts answered Steinberg's invitation to serve in the committee in the positive.

Steinberg divided the committee into four sub-committees: Medical, comprised of 26 experts; legal, comprised of 13 experts; Halachic, comprised of 7 orthodox rabbis, and philosophical/values, comprised of 12 experts. The Halachic subcommittee evoked concerns among some committee members. Although they did not object to reflect the role of religion in the debates and its significant place in the framing of the law, at the same time they felt that the Halachic subcommittee did not reflect the rainbow of religious stances in Israel. Asa Kasher, who was nominated to lead the philosophical subcommittee approached Steinberg and proposed to enlarge the scope of this subcommittee to include "values," by this he meant other forms of religion. Steinberg consented, and Kasher invited one Islamic authority, one Greek-Catholic authority, one Druze authority, one Jewish-conservative authority, and one Jewish-reform authority to serve on the philosophy/values subcommittee.

The deliberations of the subcommittees continued until 2002. Avraham Steinberg served on all the subcommittees that met separately in different places. At the start

⁷⁶ Basic Law: Human Dignity and Liberty, 1992, S.H. 150. An English translation of the law is available at http://www.knesset.gov.il/laws/special/eng/basic3_eng.htm.

⁷⁷ LSI Special Volume: Penal Law 5737-1977 9 (Isr.).

⁷⁸ Patients' Rights Law, 1996, S.H. 327.

of the deliberations, it was clear that it will be hard to reach a consensus in the philosophical/values subcommittee, let alone to agree with the people on the other subcommittees. Our aim was to draft a law that would be based on the values of Israel as a Jewish-democratic state; that would reflect the common denominator of the Israeli population; that would be viable, contributing to the well-being of many patients in Israel; that would be sensitive so as to minimize offence to different segments of the population. Great importance was assigned to terminology. At first the idea was to call the committee and the law “The Terminal Patient Committee/Law.” However, some members objected, saying that when we diagnose patients as “terminal,” it may seem that we are counting their days and are possibly even discouraging them from fighting for their lives. The doctor’s task is to help patients to live when they want to continue living, not to hold a clock over their heads and count their days. Thus, we decided on the term “dying patient”).⁷⁹ No less importantly, our aim was also that the law would be sensible so it could pass in the Israeli Parliament (Knesset). Thus, it was clear to all of us that compromises should be made, and that it will be impossible to cater for all the views and concerns. We aimed to reach the largest possible common denominator.

The result is a detailed law that balances between approaches and values, with an inescapable bias for the Halachic view; this is hardly surprising given the identities of the convening Health Minister and committee chairperson, and the composition of the committee. Yet I should say with all fairness that 80% of the members agreed on all the paragraphs of the proposed law, and 100% agreed on 95% of the paragraphs.⁸⁰ The law relates to competent as well as incompetent patients of all ages, and to the array of treatments at the end of life. The autonomy principle is respected and overrides sanctity of life considerations by permitting the withholding of any treatment directly related to the dying process, if this was the clear and known wish of the patient. The law speaks of the role of the patients’ loved people (on purpose the law does not speak of “family” as members of the committee thought that the medical team should pay attention to the opinions of the people around the patient’s bed, who attend the patient during his/her last hours. These people are conceived more important than

⁷⁹ Cf. Cohen-Almagor, *Language and Reality at the End of Life*, *supra* note 16, at 267-78.

⁸⁰ Avraham Steinberg & Charles L. Sprung, *The Dying Patient: New Israeli Legislation*, 32 *INTENSIVE CARE MEDICINE* 1235 (Aug. 2006). Most disagreements revolved around the extent of autonomy enjoyed by patients, where committee members pressed for further autonomy on the part of the patients to request ceasing array of treatments at the end of life.

possible blood relatives who fail to visit the patient).⁸¹ The law also stipulates the establishment of institutional and national ethics committees whose role will be to ponder and find answers to ethical dilemmas raised by patients, their loved ones, and the medical professionals.

The law distinguishes between continuous and intermittent treatment. By continuous treatment it is meant any form of treatment that is essentially uninterrupted and admits of no clear distinction between the end of one cycle and the beginning of another. Intermittent treatment is treatment that begins and ends in well-defined cycles.⁸² Mechanical ventilation is an example of continuous treatment, while blood transfusions, dialysis, or antibiotics are examples of discrete treatment.

According to Jewish law, it is forbidden to terminate continuous medical treatment, unless it is done for the purpose of medical treatment, when the termination may lead to the death of the patient, whether competent or not competent. However, it is permitted to terminate intermittent treatment. A patient may therefore request not to renew intermittent treatment that has been interrupted, but he/she cannot request to withdraw continuous treatment, e.g. mechanical ventilation. As continuous unwanted ventilation might prolong suffering, the law allows the possibility of changing the ventilator from a continuous form of treatment to an intermittent form by connecting a timer and allowing the ventilator to stop intermittently. The technology that turns the ventilator into an intermittent form of therapy defines the interruption as an omission rather than commission.⁸³

Thus, for instance, the timer could be set in advance for a certain period of time, say, a week, at the end of which it will be turned off without human intervention. This will allow time for appropriate discussion among the patient, his/her loved ones, and healthcare providers. The discussion may result in a decision to extend the operation of the ventilator for an additional period of time or let it be turned off at the original set time, with the patient being under appropriate sedation.⁸⁴

The authors of the Israel national report wrote that the law does not provide a solution for unconscious patients if their life expectancy exceeds six months.⁸⁵ This

⁸¹ Cf. Raphael Cohen-Almagor, *The Patients' Right to Die in Dignity and the Role of Their Beloved People*, 4 ANNUAL REV. L. & ETHICS (1996).

⁸² The Dying Patient Law, *supra* note 13, Definitions.

⁸³ Steinberg & Sprung, *supra* note 80, at 1236.

⁸⁴ Vardit Ravitsky, *Timers on Ventilators*, 330 BMJ 416 (2005).

⁸⁵ Ruth Kannai & Lea Vizek, *Euthanasia in Israel*, in EUTHANASIA IN INTERNATIONAL AND COMPARATIVE PERSPECTIVE, *supra* note 5, at 159.

is correct. The law does not intend to address this category of patients, as they are not considered to be dying. We needed to define the term “dying” and decided that the cutting line should be six months of expecting living until death takes its toll. Thus for this matter the law also does not address conscious patients whose life expectancy is longer than six months. A dying patient is defined as a person who is expected to die within six months despite medical treatment. The last two weeks of expected life are defined as the final stage.

The age of capacity is seventeen.⁸⁶ We had vivid discussions on this issue. Some argued that the age of maturity is eighteen, and therefore opted to set this age in this context as well. Others argued that sixteen-old patients who suffer from cancer are forced to think as adults, given their situation. At the end the middle way solution was reached.

Significant importance is assigned to palliative care treatment. 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.⁸⁷ The *Dying Patient Law* stipulates that medical staff must examine whether it is possible to prevent or to ease the pain by means of medication and palliative care.⁸⁸ We conceived this provision as crucial, as sometime the patient’s decision might be influenced by severe pain.⁸⁹ In this context, Ganzini and colleagues reported that as a result of palliative care, some patients in Oregon changed their minds about assisted suicide.⁹⁰

The law explicitly prohibits active euthanasia and PAS.⁹¹ I was the only committee member that suggested including a provision for PAS. In one of my books, I gave

⁸⁶ The Dying Patient Law, *supra* note 13, at ch. 3.

⁸⁷ WORLD HEALTH ORGANIZATION, *CANCER PAIN RELIEF AND PALLIATIVE CARE: REPORT OF A WHO EXPERT COMMITTEE* 11 (1990).

⁸⁸ The Dying Patient Law, *supra* note 13, at ch. 4.

⁸⁹ On the different conceptions of pain that physicians and patients have, see William Ruddick, *Do Doctors Undertreat Pain?*, 11 *BIOETHICS* 246-55 (1997). It is argued that pain control represents an often neglected need of nursing home residents, and that nursing home staff underestimate the true pain burden experienced by residents. See Joan M. Teno, Sherry Weitzen, Terrie Wetle & Vincent Mor, *Persistent Pain in Nursing Home Residents*, 285 *JAMA* 2081 (Ap. 25, 2001).

⁹⁰ Linda Ganzini, Heidi D. Nelson, Terri A. Schmidt, Dale F. Kraemer, Molly A. Delorit, & Melinda A. Lee, *Physicians’ Experiences with the Oregon Death with Dignity Act*, 342 *NEW ENG. J. MEDICINE* 563 (Feb. 24, 2000). See also R. Sean Morrison & Diane E. Meier, *Palliative Care*, 350 *NEW ENG. J. MEDICINE* 2582-90 (June 17, 2004).

⁹¹ The Dying Patient Law, *supra* note 13, at ch. 4.

the following example which was inspired by discussions and communications I had with Isaiah Berlin on end-of-life: Consider a person named James who suffers from a malignant disease that spreads through the body and slowly destroys it. The physicians must amputate his leg, but they cannot stop the endemic process that paralyses the limbs and eats the body. The physicians are able only to relieve his pain. They explain to James that the disease is without remedy. James obviously suffers, but acknowledging his fate, refuses to accept treatment. He wants to die. James shares his feelings with the doctors, telling them that his suffering is both physical and emotional because it is difficult for him to witness the anguish of his beloved people who surround his bed day and night. This patient specifically states:

I have lived my life; I have said what I had to say; I feel I lived a full and meaningful life to the best of my abilities. In my current position, I no longer find life an appealing option. I suffer and my condition causes suffering to my dear ones. In essence, all I do is to wait for death to redeem me from my misery. There is no point in prolonging this situation. Allow me to die with dignity. Dying will dignify me more than the continuation of a pointless life that damages my bones, my body, my soul, and my mind. If I were able, I would commit suicide, but I cannot. Please help me die now.⁹²

His physicians suggest the option of a hospice but James declines the offer. He wants to die now, not in several months. James explains that the medicine meant to help him cope with pain is not a useful solution for him because the suffering is not only physical. The patient feels appalled at his own feebleness, wretchedness, and dependency upon others. The suffering is psychological too, deeply touching his soul, causing him to feel that one of the things dearest to him—human dignity—is disappearing while no one can stop the process of physical deterioration.

In such a case, the correct policy is the one that respects the patient's wish and includes measures to hasten the end. Physicians should be allowed to provide assisted-suicide. The important thing is to ease the patient into a final, peaceful rest, and to show respect by fulfilling his request. To continue living is clearly painful for him by his own admission. Doctors who would be willing to entertain this reasoning

⁹² RAPHAEL COHEN-ALMAGOR, *THE RIGHT TO DIE WITH DIGNITY: AN ARGUMENT IN ETHICS, MEDICINE, AND LAW* ch. 4 (2001).

would also recognize their duty to help the patient when he cannot help himself. For a small minority of patients, the continuation of living at all costs is not an appealing option. These patients should not be ignored. Medicine and ethics should address their needs. Although not an easy task, the solution must not be beyond our reach either medically or ethically. That solution might change the nature of medicine but the “nature of medicine” is not a static concept. It is in constant flux and through the ages it has developed by using different standards and norms (see, for instance, the agenda and terminology of the Hippocratic Oath). The history of the last forty years shows that medicine has changed dramatically due to rapid technological developments. These same developments make it possible to prolong life in difficult situations. An acrobatic argument that acknowledges technological advances but dismisses the evolving ethical issues that pose uncomfortable and disturbing questions is unfair to the community of patients. Alas, I was unable to convince my colleagues to join my position.

Some thought that the idea of PAS is objectionable, while others approved PAS on the moral level, yet thought that the consensus in Israel would not support PAS, and the law will not pass in the Knesset with the inclusion of this provision.

A special chapter of the law (Chapter 5) relates to the expression of prior wishes.⁹³ Advance directives can be provided only in writing, on a specific form, in the presence of two witnesses who have no economic or other interest of potential gain resulting from the death of the author of the directives. Advance directives are valid for five years, and then need to be refreshed and resigned.⁹⁴ Testimonials about the wishes of incompetent dying patient by his/her loved ones are accepted. The law regulates the establishment of a database in which advance directives and powers of attorney are to be recorded.⁹⁵ The Dying Patient Law also provides for the appointment of surrogate decision-maker and the establishment of problem-solving mechanisms for various dilemmas.

⁹³ The Dying Patient Law, *supra* note 13, at ch. 5.

⁹⁴ *Id.*

⁹⁵ Kannai & Vizel, *supra* note 85, at 164. For further deliberation, see Bechor Zvi Aminoff, *The New Israeli Law 'The Dying Patient' and Relief of Suffering Units*, 24 AM. J. HOSPICE AND PALLIATIVE MEDICINE 54-58 (2007).

D. *The United States*

Surprisingly, the chapter on the United States contains only one paragraph about Oregon's Death with Dignity Act.⁹⁶ Most of this report deals with case law on withholding and withdrawing treatment.

Oregon is known for its independent and progressive streak. About 90% of Oregonians are white and research has shown that whites are more likely than minorities (particularly African-Americans and Hispanics) to support PAS.⁹⁷ In addition, Oregon is a relatively secular state where religious sentiments are not strong. That factor allows Oregonians to espouse moral views that do not necessarily coincide with religious norms.⁹⁸ Chet Orloff, Director of the Oregon Historical Society, explained: "This measure is in keeping with Oregon. Throughout history Oregon seems to be out there ahead of other states in testing things."⁹⁹

Oregon has the country's first and only physician-assisted suicide law. Its voters approved the Death with Dignity Act in 1994 and again in 1997. The law allows Oregonian patients who suffer from an incurable disease and who have a life expectancy of no more than six months to receive prescriptions for self-administered lethal medications from their physicians. The Act legalizes only PAS, stating that "nothing in this Act shall be construed to authorize a physician or any other person to end a patient's life by lethal injection, mercy killing or active euthanasia."¹⁰⁰ It permits a capable¹⁰¹ adult¹⁰² Oregon resident¹⁰³ diagnosed with a "terminal" disease

⁹⁶ Richard S. Kay, *Causing Death for Compassionate Reasons in American Law*, in *EUTHANASIA IN INTERNATIONAL AND COMPARATIVE PERSPECTIVE*, *supra* note 5, at 261.

⁹⁷ U.S. BUREAU OF THE CENSUS, *STATISTICAL ABSTRACT OF THE UNITED STATES* (1997); P.V. Caralis, Bobbi Davis, Karen Wright & Eileen Marcial, *The Influence of Ethnicity and Race on Attitudes Toward Advance Directives, Life Prolonging Treatment, and Euthanasia*, 4 J. CLINICAL ETHICS 155, 57-59 (1993) and see <http://www.oregon.gov/DHS/ph/pas/docs/statute.pdf>.

⁹⁸ A study released on February 25, 2008 by the Pew Forum on Religion and Public Life, found that 27 percent of Oregonians are unaffiliated with any religion, compared with 16% of all Americans nationally. No other state has a higher percentage of unaffiliated adults. See <http://religions.pewforum.org/maps>.

⁹⁹ Tom Bates & Mark O'Keefe, *Suicide Law Reflects Oregon Politics: Voters Tend to Be Quirky But Consistent in Maverick State*, PLAIN DEALER (Clev.), Nov. 21, 1994, at 3E.

¹⁰⁰ The Oregon Death with Dignity Act § 3.14, OR. REV. STAT. § 127.880 (1999).

¹⁰¹ "Capable" is defined as having the ability to make and communicate health care decisions to a health care provider. See Oregon Death With Dignity Act § 1.01(3), OR. REV. STAT. § 127.800 (1999).

¹⁰² An "adult" is an individual who is at least eighteen years of age. Oregon Death with Dignity Act § 1.01(1), OR. REV. STAT. § 127.800 (1999).

¹⁰³ Oregon Death With Dignity Act § 3.10, OR. REV. STAT. § 127.860 (1999). The residency requirement was intended to prevent individuals from other states from rushing to Oregon to take advantage of

to “make a written request for medication for the purpose of ending his or her life in a humane and dignified manner . . .”¹⁰⁴ Physicians who write such prescriptions in good-faith compliance with the Act are shielded from civil or criminal penalties and professional discipline.¹⁰⁵

The reasoning behind the Act recognizes that a person may face grave difficulties at the end of his/her life. The general argument of death-with-dignity advocates focuses on a special set of circumstances where (1) a person has a deadly disease; (2) is capable; and (3) has made the request to end his/her life voluntarily. The viewpoint is that although a person’s life is always valuable, a patient’s desire to control his or her manner of death and to die a more painless and/or dignified death should be given precedence over the value of his/her life.¹⁰⁶ In order to protect the individual’s freedom to act, two rights are recognized: the right to autonomy and the right to choice in end-of-life issues. Both of these rights were cited by family members as extremely important reasons why patients chose PAS.¹⁰⁷

In a decade, fewer than 300 people have died under the terms of the law. Far more people request the lethal prescription than use it. The majority of those who do use it are older and more educated than the average Oregonian, according to state data. As is the case in The Netherlands and in Belgium, most of the requests are initiated by cancer patients. Their primary end-of-life concerns are about dignity, autonomy and the ability to participate in activities that made life enjoyable.¹⁰⁸

It is argued that palliative and hospice care has increased markedly in Oregon because the law helped raise awareness about caring for incurably ill patients. As

the Act. Annette E. Clark, *Autonomy and Death*, 71 TULANE L. REV. 45 n.43 (1996).

¹⁰⁴ Oregon Death With Dignity Act § 2.01, OR. REV. STAT. § 127.805 (1999). Voluntary euthanasia occurs when an individual, usually a physician, administers a lethal drug at a patient’s request, thus producing the patient’s death. David Orentlicher, *Physician Participation in Assisted Suicide*, 262 JAMA 1844 (1989).

¹⁰⁵ Oregon *Death With Dignity Act* § 4.01(1), OR. REV. STAT. 127.885 (1999). Without this provision, physicians who assisted a suicide would be civilly and criminally liable under OR. REV. STAT. § 163.125 (1995), which makes it a crime to intentionally cause or aid another in committing suicide.

¹⁰⁶ See generally, COHEN-ALMAGOR, THE RIGHT TO DIE WITH DIGNITY, *supra* note 92.

¹⁰⁷ Amy D. Sullivan, Katrina Hedberg & David W. Fleming, *Legalized Physician-Assisted Suicide in Oregon—the Second Year*, 342 NEW ENG. J. MEDICINE 598, 603 (2000); Raphael Cohen-Almagor & Monica G. Hartman, *The Oregon Death with Dignity Act: Review and Proposals for Improvement*, 27 J. LEGISLATION 269-98 (2001).

¹⁰⁸ Sarah Skidmore, *Oregon’s Death with Dignity Law Reaches 10-year Milestone*, ASS’T PRESS, Oct. 26, 2007.

a result, Oregon ranks among the best in the United States in end-of-life care. This means more people are looked after at home with the emotional and spiritual support of their families rather than spending their last days in a hospital.¹⁰⁹ The Oregon policy and practice of PAS may serve as a good model for other nations to follow.

V. *Conclusions*

For the second edition of this volume, I propose the following constructive suggestions:

The title should better reflect the book's content. It should be accurate and precise. I propose amending the title to read: *End-of-Life Considerations in Fourteen Jurisdictions*.

The chapters on France and Iran are written in French. For unity and coherence, I urge translation into English. I also suggest beefing up the Iranian report, which presently consists of a mere two pages.

There should be a concluding chapter that would provide a comparative study of the different jurisdictions, and based on their experience offer suggestions for improvement. Indeed, based on the experiences of the fourteen jurisdictions, I'd like to propose the following guidelines for PAS in the democratic world. Patients in a devastating situation, who wish to cease living, if helped by a physician, are helped to relieve their suffering. The motivation is to assist one's fellow by providing relief from enduring suffering. The decision to help patients end their lives is first and foremost a *moral* decision. There are competent, adult patients who feel that the preferable way for them to part from life is through PAS. I propose a circumscribed plea for voluntary PAS on their behalf.

Guideline 1. The physician should not initiate discussion about assisted suicide to the patient, highlighting this practice among all practices. Instead, it is the patient who should have the option to ask for such assistance. Emphasizing PAS by the physician might undermine the trust between the patient and the physician, conveying

¹⁰⁹ Right to Die Listserv, *Oregon Takes Stock of "Right to Die" Law* (Mar. 12, 2007), available at <http://assistedsuicide.org>.

to patients that the doctor is giving up on them and values their lives only to the extent of offering assistance to die. Such an offer might undermine the will to live and to explore further avenues for treatment.

Guideline 2. The request for PAS of an adult,¹¹⁰ competent patient who suffers from an intractable, incurable and irreversible disease must be voluntary.¹¹¹ The decision is that of the patient who asks to die without pressure, because life appears to be the worst alternative in the current situation. The patient should state this wish repeatedly over a period of time.¹¹² We must verify that the request for PAS does not stem from a momentary urge, an impulse, a product of passing depression. This emphasis of enduring request was one of the requirements of the abolished Northern Territory law in Australia,¹¹³ and is one of the requirements of the Oregon Death with Dignity Act,¹¹⁴ as well as of the Dutch Guidelines.¹¹⁵ We must also verify that the request is not the result of external influences. It should be ascertained with a signed document that the patient is ready to die now, rather than depending solely upon directives from the past. Section 2 of the Oregon Act requires that the written request for medication to end one's life be signed and dated by the patient and witnessed by at least two individuals who, in the presence of the patient, attest to the best of their knowledge and belief that the patient is capable, is acting voluntarily, and is not being coerced to sign the request.¹¹⁶

¹¹⁰ Most bill proposals to legislate PAS in the United States specify that the age of the consenting patient must be 18 or older to qualify for the procedure. Russell Korobkin, *Physician-assisted Suicide Legislation: Issues and Preliminary Responses*, 12 NOTRE DAME J. L. ETHICS & PUBLIC POLICY 454 (1998).

¹¹¹ See the Dutch requirements of careful practice, in JOHN GRIFFITHS, ALEX BOOD & HELEEN WEYERS, *EUTHANASIA AND LAW IN THE NETHERLANDS* 66 (1998). See also ch. II. Article 3 of the Belgian Euthanasia Law, *supra* note 38 and the Nagoya High Court requirements in *EUTHANASIA IN INTERNATIONAL AND COMPARATIVE PERSPECTIVE*, *supra* note 5, at 189.

¹¹² Many bill proposals to legislate PAS in the United States require a waiting period of 14 or 15 days. Cf. Korobkin, *supra* note 110, at 468.

¹¹³ Section 7, Rights of the Terminally Ill Act (1995) (NT) (Australia).

¹¹⁴ In Australia, the law required a "cooling off" period of nine days. In Belgium, the law requires a "cooling off" period of one month. In Oregon, the Act requires a waiting period of fifteen days. I do not wish to suggest an arbitrary time period of waiting, saying instead that the patient should state his/her wish several times "over a period of time." I concur with Miller and colleagues who think that a fifteen days waiting period may be highly burdensome for patients who are suffering intolerably and may preclude access to assisted death for those who request it at the point when they are imminently dying. See Franklin G. Miller, Howard Brody & Timothy E. Quill, *Can Physician-Assisted Suicide Be Regulated Effectively?*, 24 J. LAW, MEDICINE & ETHICS 226 (1996). See also Oregon, *Death with Dignity Act*, <http://www.oregon.gov/DHS/ph/pas/docs/statute.pdf>.

¹¹⁵ GRIFFITHS, BOOD & WEYERS, *supra* note 111, at 66.

¹¹⁶ Death with Dignity Act, OR. REV. STAT., *supra* note 114.

Individuals may express general attitudes regarding euthanasia in an informal discussion made in a social setting, possibly saying that they would not want to live if they were unable to function alone and had to depend on the mercy of others. However, such hypothetical observations do not constitute reliable evidence of a patient's current desires once an actual illness is in progress. This is especially true if the wish was stated when young and healthy. The tendency to come to terms with suffering, to compromise with physical disabilities, and to struggle to sustain life grows as the body weakens. Many people change their minds when they confront the unattractive alternatives, preferring to remain in what others term the "cruel" world, and continue the Sisyphean struggle for their lives.¹¹⁷

Guideline 3. At times, the patient's decision might be influenced by severe pain.¹¹⁸ A Belgian study shows that the most frequent physical suffering is pain, followed by exhaustion and cachexia.¹¹⁹ In this context, the role of palliative care can be crucial. The medical staff must examine whether it is possible to prevent or to ease the pain by means of medication and palliative care.¹²⁰ 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.¹²¹ A study designed to examine Oregon physicians' attitudes toward and practices regarding care of dying patients since the passage of the Act shows that 30% of the 791 respondents reported that they had increased referrals to hospice. Of the 2094 respondents who cared for patients termed "terminally ill," 76 % reported that they made efforts to improve

¹¹⁷ See COHEN-ALMAGOR, THE RIGHT TO DIE WITH DIGNITY, *supra* note 92.

¹¹⁸ See the November 12, 2003 issue of JAMA and <http://www.pain.com>; <http://www.wellcome.ac.uk/en/pain/index.html>; <http://plato.stanford.edu/entries/pain>.

¹¹⁹ EUTHANASIA IN INTERNATIONAL AND COMPARATIVE PERSPECTIVE, *supra* note 5, at 39.

¹²⁰ Directive 7, 2/96 THE GENERAL MANAGER CIRCULAR (Israel Ministry of Health) 12 (Jan. 31, 1996) holds: "Doctors must concentrate their efforts on easing the pain, torment, and suffering of the patient, a subject of highest priority in medical treatment, especially when terminal patients are concerned," [in Hebrew] (translated R.C.-A.). Israel's Dying Patient Law includes a provision for palliative care. For further deliberation on pain control mechanisms and their importance, see Timothy E. Quill, Bernard Lo, & Dan W. Brock, *Palliative Options of Last Resort*, 278 JAMA 2099-104 (Dec. 17, 1997); TEXTBOOK OF PALLIATIVE MEDICINE (P. D. Doyle, G. W. Hanks, & N. MacDonald eds., 1998); Timothy E. Quill, Barbara Coombs-Lee & Sally Nunn, *Palliative Treatments of Last Resort: Choosing the Least Harmful Alternative*, 132 ANNALS INTERNAL MED. 488 (March 21, 2000). For further discussion on making palliative care decisions for *incompetent* patients, see Jason H.T. Karlawish, Timothy Quill, & Diane E. Meier, *A Consensus-Based Approach to Providing Palliative Care to Patients Who Lack Decision-Making Capacity*, 130 ANNALS OF INTERNAL MED. 835-40 (May 18, 1999).

¹²¹ See Oregon, *Oregon Death with Dignity Act*, *supra* note 114 at § 3.01 (1998).

their knowledge of the use of pain medications.¹²² Bill proposals to legislate PAS in Illinois, Hawaii, Maine, Michigan, Vermont, Washington and Wisconsin explicitly require the attending physician to review options for palliative care with the patient, including hospice and/or pain control options.¹²³ If it is possible to prevent or to ease the patient's pain, then the patient's request for PAS should not be fulfilled; instead, the necessary treatment should be prescribed. This is provided that the educated patient (i.e., a patient who was advised by the medical staff about the available palliative care options) does not refuse to take the painkillers, and that when the pain subsides so does the motive (or one of the main motives) for assisted suicide. If the patient insists on denying all medication, then doctors must first try to find the appropriate healing method before they comply with the request.¹²⁴

Coping with pain and suffering can drain all of the patient's emotional strength, exhausting the ability to deal with other issues. In cases of competent patients, the assumption is that the patient understands the meaning of the decision. A psychiatrist's assessment can confirm whether the patient is able to make a decision of such ultimate significance to the patient's life and whether the decision is truly that of the patient, expressed consistently and of his/her own free will. The Northern Territory *Rights of Terminally Ill Act* required that the patient meet with a qualified psychiatrist to confirm that the patient was not clinically depressed.¹²⁵ It is worthwhile to hold several such conversations, separated by a few days. The patient's loved ones and the attending physician should be included in at least one of the conversations.

Guideline 4. The patient must be informed of the situation and the prognosis for recovery or escalation of the disease, with the suffering that it may involve. There must be an exchange of information between doctors and patients.¹²⁶ Bearing this in

¹²² Linda Ganzini, Heidi D. Nelson, Melinda A. Lee, Dale F. Kraemer, Terri A. Schmidt & Molly A. Delorit, *Oregon Physicians' Attitudes About and Experiences With End-of-Life Care Since Passage of the Oregon Death with Dignity Act*, 285 JAMA 2363-69 (2001).

¹²³ Korobkin, *supra* note 110, at 469.

¹²⁴ J. V. Lavery, Joseph Boyle, Bernard M. Dickens, Heath Maclean, & Peter A. Singer, *Origins of the Desire for Euthanasia and Assisted Suicide in People with HIV-1 or AIDS: A Qualitative Study*, 358 LANCET 362 (Aug. 4, 2001). See also Anthony L. Back & Robert A. Pearlman, *Commentary: Desire for Physician-assisted Suicide: Request for a Better Death?*, 358 LANCET 344 (Aug. 4, 2001).

¹²⁵ Section 7, Rights of the Terminally Ill Act, *supra* note 113.

¹²⁶ On this issue, see Death with Dignity Act, OR. REV. STAT. § 3, *supra* note 114, attending physician responsibilities. Many bill proposals to legislate PAS in the United States specify certain information that must be communicated by the physician to the patient before honoring his/her request. Cf. Korobkin, *supra* note 110, at 468. See also Chap. II, Article 3 of the Belgian

mind, we should be careful to use neutral terms and to refrain from terms that might offend patients and their loved ones.¹²⁷

Guideline 5. 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 are a burden to 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). A situation could exist in which the patient is under no such pressure, but still does not wish to be a burden on others. Obviously, we cannot say that the feelings of patients toward their loved ones are not relevant to the decision-making process.¹²⁸

Guideline 6. The decision-making process should include a second opinion in order to verify the diagnosis and minimize the chances of misdiagnosis, as well as to allow the discovery of other medical options. A specialist, who is not dependent on the first doctor, either professionally or otherwise, should provide the second opinion.¹²⁹ The patient's attending physician, who supposedly knows the patient's case better than any other expert, must be consulted, and all reasonable alternative treatments must be explored. The Oregon Death with Dignity Act requires that a consulting physician shall examine the patient and his/her relevant medical records and subsequently confirm, in writing, the attending physician's diagnosis that "the patient is suffering from a terminal disease." Furthermore, the consulting physician must verify that the patient is capable, is acting voluntarily, and has made an informed decision.¹³⁰ The Dutch Guidelines require that the physician consult a colleague.¹³¹

Euthanasia Law, *supra* note 38. Israel Patients' Rights Law, *supra* note 78 provides that the patient should be provided with all the information necessary for making informed consent.

¹²⁷ Cohen-Almagor, *supra* note 7, at 267-78. See also S.E. Bedell, T.B. Graboys, E. Bedell, & B. Lown, *Words That Harm, Words That Heal*, 163 ARCH INTERN MED. 1365-68 (July 12, 2004).

¹²⁸ COHEN-ALMAGOR, THE RIGHT TO DIE WITH DIGNITY, *supra* note 92, at ch. 6; John Hardwig, *Families and Futility: Forestalling Demands for Futile Treatment*, 16 J. CLINICAL ETHICS 328-337 (2005).

¹²⁹ Most bill proposals to legislate PAS in the United States required that the treating physician refer the patient to a second consulting physician to verify the terminal nature of the disease. The Massachusetts bill required a third confirming opinion. Cf. Korobkin, *supra* note 111, at 453. See also Chap. II, Article 3 of the Belgian Euthanasia Law, *supra* note 38.

¹³⁰ Oregon *Death with Dignity Act*, <http://www.oregon.gov/DHS/ph/pas/docs/statute.pdf> The American Medical Association's council on ethical and judicial affairs suggests the participation of consultants to facilitate discussions that would help the parties reach a course of action. AMA strongly objects to PAS. See Fred Charatan, *AMA Issues Guidelines on End of Life Care*, 318 BMJ 690 (Mar. 13, 1999).

¹³¹ GRIFFITHS, BOOD & WEYERS, *supra* note 112, at 66 & 104.

The Northern Territory Rights of Terminally Ill Act required that a physician who specialized in treating terminal illness examine the patient.¹³²

Guideline 7. It is advisable for the identity of the consultant to be determined by a small committee of specialists similar to the Dutch Support and Consultation of Euthanasia (SCEN) project that was initiated to provide all general practitioners with a support group for consultation or advice on euthanasia and PAS. The purpose was not only to make it easier for general practitioners to find an independent and knowledgeable consultant, but also to make the consultation more professional.¹³³ SCEN provides a telephone service that enables doctors to speak with trained, professional staff that can offer practical medical or legal advice or arrange a formal consultation. Staff follows a consultation protocol and a written record of consultations is kept.¹³⁴ Physicians are required to contact SCEN consultants before they perform euthanasia, in order to make consultation as effective as possible. Such committee of specialists is required in order to avoid the possibility of arranging deals between doctors (“you will consult for me regarding Mr. Jones, approving my decision, and I will consult for you regarding Ms. Smith, approving your decision”).¹³⁵

Guideline 8. Some time prior to the performance of PAS, a doctor and a psychiatrist are required to visit and examine the patient so as to verify that this is the genuine wish of a person of sound mind who is not being coerced or influenced by a third party. The conversation between the doctors and the patient should be held without the presence of family members in the room in order to avoid familial pressure. A date for the procedure is then agreed upon.¹³⁶ The patient’s loved ones will be notified so that they can be present right until the performance of the act, making the day an intimate, family occasion.

¹³² Section 7, Rights of the Terminally Ill Act, *supra* note 113.

¹³³ BREGJE ONWUTEAKA-PHILIPSEN, CONSULTATION OF ANOTHER PHYSICIAN IN CASES OF EUTHANASIA AND PHYSICIAN-ASSISTED SUICIDE 91 (1999).

¹³⁴ Tony Sheldon, *Netherlands Sets Up Euthanasia Advisory Body*, 318 BRIT. MEDICAL J. 348 (Feb. 6, 1999).

¹³⁵ In this context, for further discussion see Reginald Deschepper, et. al, *Communication on End-of-life Decisions with Patients Wishing to Die at Home: the Making of a Guideline for General Practitioners in Flanders, Belgium*, 56 BRIT. J. GENERAL PRACTICE 14-19 (Jan. 1, 2006), available at <http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=1828069>.

¹³⁶ Proposals to legislate PAS in Illinois, Massachusetts, and Maine required that a patient seeking PAS obtain a consultation with a mental health professional in order to insure that the patient can pass the “impaired judgment” standard. *Cf.* Korobkin, *supra* note 110, at 456. This Guideline is somewhat similar to the guidelines of the Swiss EXIT protocol.

Guideline 9. The patient can rescind at any time and in any manner. This provision was granted under the Australian Northern Territory Act¹³⁷ and under the Oregon *Death with Dignity Act*.¹³⁸ Chapter III, Article 4 of the Belgian Euthanasia Law says that patients can withdraw or adjust their euthanasia declaration at any time.¹³⁹

Guideline 10. PAS may be performed only by a doctor and in the presence of another doctor.¹⁴⁰ The decision-making team should include at least two doctors and a lawyer, who will examine the legal aspects involved. Insisting on this protocol would serve as a safety valve against possible abuse. Perhaps a public representative should also be present during the entire procedure, including the decision-making process and the performance of the act. This extra caution should ensure that the right to die with dignity does not become a duty. The doctor performing the assisted suicide should be the one who knows the patient best, having been involved in the patient's treatment, taken part in the consultations, and verified through the help of social workers, nurses and psychologists that euthanasia is the true wish of the patient.

Guideline 11. PAS may be conducted in one of three ways, all of them discussed openly and decided upon by the physician and the patient together: (1) oral medication; (2) self-administered, lethal intravenous infusion; (3) self-administered lethal injection. Oral medication may be difficult or impossible for many patients to ingest because of nausea or other side effects of their illnesses. In the event that oral medication is provided and the dying process lingers on for long hours, the physician is allowed to administer a lethal injection.¹⁴¹

Guideline 12. Doctors may not demand a *special fee* for the performance of assisted suicide. The motive for PAS is humane, so there must be no financial incentive and no special payment that might cause commercialization and promotion of such procedures.

¹³⁷ Plattner, *supra* note 10, at 648.

¹³⁸ 13 OR. REV. STAT. § 3.07 (1998).

¹³⁹ Chamber of the Representatives of Belgium, *Government Bill Related to Euthanasia* (Nov. 5, 2001), Doc 5014488/001, project transmitted by the Senate, available at <http://www.kuleuven.ac.be/cbmer/viewpic.php?LAN=E&TABLE=DOCS&ID=23>

¹⁴⁰ See the Nagoya High Court requirements, in EUTHANASIA IN INTERNATIONAL AND COMPARATIVE PERSPECTIVE, *supra* note 5, at 189.

¹⁴¹ Cf. Johanna H. Groenewoud, Agnes van der Heide, Bregje D. Onwuteaka-Philipsen, et al., *Clinical Problems with the Performance of Euthanasia and Physician-assisted Suicide in the Netherlands*, 342 NEW ENG. J. MED. 551-56 (2000).

Guideline 13. 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 PAS; 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 his/her request; documentation of discussions with the patient's loved ones; and a psychological report confirming the patient's condition. 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 PAS.¹⁴²

Guideline 14. Pharmacists should also be required to report all prescriptions for lethal medication, thus providing a further check on physicians' reporting.¹⁴³

Guideline 15. Doctors must not be coerced into taking actions that contradict their conscience or their understanding of their role. This was provided under the Northern Territory Act.¹⁴⁴

Guideline 16. 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 Guidelines.

Guideline 17. Licensing sanctions will be taken to punish those health care professionals who violated the Guidelines, failed to consult or to file reports, engaged in involuntary euthanasia without the patient's consent or with patients lacking proper decision-making capacity. Physicians who failed to comply with the above Guidelines will be charged and procedures to sanction them will be brought by the Disciplinary Tribunal of the Medical Association. The maximum penalty for violation of the Guidelines will be the revoking of the physician's medical license. In the event that

¹⁴² *Directive 6, 2/96 THE GENERAL MANAGER CIRCULAR* (Israel Ministry of Health) 12 (Jan. 31, 1996) states: "The decision to respect a patient's objection to a life prolonging treatment shall be documented in the medical statutes, expressing maximum reasons for the decision and the discussions with the patient," [in Hebrew] (translated R.C.-A.). See also Israel Patients' Rights Law, *supra* note 78, at 331, Chapter E: medical documentation and medical information. In addition, Israel's Dying Patient Law, *supra* note 13 includes a provision for detailed documentation.

¹⁴³ For further deliberation, see Johan Bilsen, Marc Bauwens, Jan Bernheim, et al., *Physician-Assisted Death: Attitudes and Practices of Community Pharmacists in East Flanders, Belgium*, 19 *PALLIATIVE MEDICINE* 151-57 (2005).

¹⁴⁴ Plattner, *supra* note 10, at 648.

this penalty proves insufficient in deterring potential abusers, there will be room to consider further penalties, including heavy fines and prison sentences.¹⁴⁵

Lastly, for the second edition I would urge preparation of a comprehensive Index. This is a most useful tool for such academic books and for lawyers who usually struggle for time. I, for one, am hesitant to purchase a book that lacks a detailed index.

¹⁴⁵ For further deliberation, see Arthur L. Caplan, Lois Snyder, & Kathy Faber-Langendoen, *The Role of Guidelines in the Practice of Physician-Assisted Suicide*, 132 ANNALS OF INTERNAL MEDICINE 476-81 (Mar. 21, 2000); S. Frileux, C. Lelièvre, M. T. Muñoz Sastre, E. Mullet, & P. C. Sorum, *When Is Physician Assisted Suicide or Euthanasia Acceptable?*, 29 J. MEDICAL ETHICS 330-36 (Dec. 1, 2003).