From:

Subject: DONNELLY, Greg Submission - Inquiry into End of Life Choices

Date: Monday, 31 August 2015 12:17:28 PM
Attachments: 1 2R Rights oF the Terminally III Bill 2013.pdf

2 SCHADENBERG Alex - Exposing Vulnerable People to Euthanasia & Assisted Suicide Alex Schadenberg

Austraian Version.pdf

3 BMB-June-2013-Somerville-and-Boudreau-euthanasia-is-not-medical.pdf

4 MB-59303-euthanasia-and-assisted-suicide physicians 071714.pdf

5 BARRON & LEMER Euthanasia in Belgium and the Netherlands On a Slippery Slope August 2015.pdf

6 ADJ Euthanasia and Physician Assisted Suicide.pdf

31<sup>st</sup> August 2015

Ms Lilian Topic
Secretary
Legal and Social Issues Committee
Parliament House
Spring Street
EAST MELBOURNE VIC 3002

Dear Ms Topic,

## RE: Standing Committee on Legal and Social Issues (Legislation and Reference) RE: Inquiry into End of Life Choices

Thank you for the opportunity to make a contribution to the abovementioned inquiry. My submission takes the form of providing some specific references to the Standing Committee that I hope will assist its deliberations into this important social policy matter. The references attached include:

### **Attachment One**

Rights of the Terminally III Bill 2013, Second Reading Speech by the Hon. Greg Donnelly MLC, NSW Legislative Council, 23<sup>rd</sup> May 2013. The Bill was defeated: 13 Ayes to 23 Noes.

#### **Attachment Two**

Schadenberg, Alex (2013) Exposing Vulnerable People to Euthanasia and Assisted Suicide. Connor Court Publishing, Ballan, Australia. The book contains in my view a significant amount of evidence to seriously contest the claim that so-called safe euthanasia or physician-assisted suicide legislation can be created and enforced.

#### **Attachment Three**

Boudreau, J. Donald, and Somerville, Margaret A. *Euthanasia is not medical treatment*. British Medical Bulletin 2013; 106: 45-66.

#### **Attachment Four**

Boudreau, J. Donald, and Somerville, Margaret A. *Euthanasia and assisted suicide: a physician's and ethicist's perspective*. Medicolegal and Bioethics 2014; 4: 1-12.

#### **Attachment Five**

Barron, Lemer H., and Caplan, Arthur L. *Euthanasia in Belgium and the Netherlands: On a Slippery Slope?*. JAMA Internal Medicine 2015 (http://archinte.jamanetwork.com/article.aspx?articleid=2426425).

#### **Attachment Six**

Euthanasia and Physician-Assisted Suicide, Adjournment Speech by the Hon. Greg Donnelly MLC, NSW Legislative Council, 26<sup>th</sup> August 2015. The Adjournment Speech summarises the key findings from research recently undertaken in Belgium and the Netherlands (attachment five).

In my respectful submission the references present a number of sound arguments to support the case that governments and legislatures should not pass laws that provide for euthanasia or physician-assisted suicide. The most recent research into the practices in both Belgium and the Netherlands (attachment five) demonstrates very clearly the great vulnerability of the elderly, the disabled, the poor, minorities and people with psychiatric impairments to any such legislation. Governments and legislatures have an overriding obligation to protect such people and must not support proposed laws that have not just the potential, but the likelihood, to threaten the lives of individuals.

If you would like me to answer further questions or give oral evidence at any hearing that may be convened regarding this matter, please call me on (02) 9230 2280.

Yours sincerely,

Greg Donnelly MLC
Parliament of New South Wales



# The Honourable Greg Donnelly MLC EUTHANASIA AND PHYSICIAN-ASSISTED SUICIDE

## **ADJOURNMENT SPEECH**

26<sup>th</sup> August 2015

Mr President,

As we have seen in this Parliament and other legislatures both here in Australia and overseas, one of the key arguments presented to oppose the introduction of euthanasia and physician-assisted suicide is the so-called "slippery slope". In simple terms the argument is that once a society takes the step to legally permit doctors to kill patients or assist patients to kill themselves, it will not be possible to limit the killing to only those who wish to die.

Those who support euthanasia and physician-assisted suicide commonly attack the argument as being selfserving and not based on evidence that can stand up to any serious scrutiny. They assert the paramount importance of individual self-determination and choice. Those who oppose euthanasia and physician-assisted suicide are characterised as insensitive and cold-hearted; demanding that a moral code be imposed on everybody, while at the same time denying citizens the right to "die with dignity".

This evening I would like to draw to the attention of Members an article recently published online in JAMA Internal Medicine on 10<sup>th</sup> August 2015. It is co-written by two well-known medical ethicists Barron Lerner and Arthur Caplan. In the article *Euthanasia in Belgium and the Netherlands: On a Slippery Slope?*, the authors reviewed the recent findings of two pieces of research into physician-assisted suicide and euthanasia from the Netherlands and Belgium respectively. It is worth noting that Arthur Caplan was a supporter of the 2012 referendum in Massachusetts to legalise assisted suicide.

Regarding the pieces of research, Lerner and Caplan note that the term slippery slope is not mentioned or used in either study. However, they state that both studies report "worrisome findings that seem to validate concerns about where these practices might lead." They go on to say that:

"These findings, and other recent data regarding the speeding of patients' deaths, make this a key moment to revisit efforts in the legalization of assisted dying in the United States and elsewhere, and, specifically, the role of the medical profession."

Regarding the research from the Netherlands Lerner and Caplan state that some of the findings are of particular concern:

"Most notably, 6.8% of those who successfully obtained euthanasia or physician-assisted suicide were categorized

as tired of living. A total of 3.7% reported only psychological suffering. Although it is possible that such people were suffering unbearably and not apt to improve, the term tired of living is vague and thus disturbing. Similarly, 49.1% of those whose requests were granted characterized part of their suffering Ioneliness. Loneliness, even if accompanied by other symptoms, hardly seems a condition best addressed by offering death. Finally, that 53.7% of approved requests are among those 80 years and older raises red flags. Is old age itself being conflated with suffering? Is it possible that there is a not-so-subtle ageism here among the physicians approving such requests?"

They further observe that 1 in 30 people in the Netherlands (3.3%) died by euthanasia in 2012. This is approximately triple the percentage in 2002 when the practice of euthanasia was legalised.

The second piece of research relates to the practice of euthanasia in Flanders, the Dutch-speaking region of Belgium. Lerner and Caplan note that in the period 2007 to 2013 the prevalence of euthanasia rose from 1.9% to 4.6% of all deaths. This represents 1 in 22 deaths. The data also indicates that the percentage of euthanasia requests that were approved increased from 55% in 2007 to 77% in 2013.

The authors also noted that "tiredness of life" became a basis of requesting euthanasia in Belgium in 2013. They further expressed concern that the fastest-growing populations receiving euthanasia include those potentially vulnerable to discrimination and stigma such as women, people older than 80 years, those with less educational attainment and nursing home residents.

Both Lerner and Caplan acknowledge that there are some gaps in the studies and more research is required. However, as they observe, this data and other recent reports require the slippery slope argument to be taken

seriously. In reflecting on the research the authors speculate that:

"... the increasing rates of euthanasia may ... represent a type of reflexive, carte blanche acquiescence among physicians concept of patient self-determination. Or worse, is it simply easier for physicians to accede to these sad and ailing patients' wishes than to re-embark on new efforts to relieve or cope with their suffering? As one Dutch ethics professor has said, 'The risk now is that people no longer search for a way to endure their suffering.' In other words, are the Belgium Netherlands and turning to physicians to solve with euthanasia what are essentially psychosocial issues?"

The authors conclude their reflections on the Netherlands and Belgium research by clearly affirming that physicians must primarily remain healers. As they correctly observe, there are numerous groups that are potentially vulnerable to abuses waiting at the end of the slippery slope – the elderly, the disabled, the poor, minorities, and people with psychiatric impairments. "When a society does poorly in the alleviation of suffering, it should be careful not to slide into trouble. Instead, it should fix its real problems."

Far from being just a debating point used by those who oppose euthanasia and physician-assisted suicide, the slippery slope is a clear and present danger that cannot and must not be ignored.

Contact details:

The Honourable Greg Donnelly MLC Legislative Council





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Invited Commentary | August 10, 2015

## **Euthanasia in Belgium and the Netherlands** On a Slippery Slope? FREE ONLINE FIRST

Barron H. Lerner, MD, PhD1; Arthur L. Caplan, PhD1

[+] Author Affiliations

JAMA Intern Med. Published online August 10, 2015. doi:10.1001/jamainternmed.2015.4086 Text Size: A A A

Article References Comments

The slippery slope is an argument frequently invoked in the world of bioethics. It connotes the notion that a particular course of action will lead inevitably to undesirable and unintended consequences. Saying no to the original action, even if that act is moral in itself, may, in light of the slope that looms, be the ethical thing

Slipperv slope arguments have been especially pervasive in discussions of euthanasia, in which physicians actively end patients' lives, and physician-assisted dving (or physician-assisted suicide), in which physicians supply medications to patients that enable them to end their own lives. 1.2 The concern, fueled by the German experience with racially motivated euthanasia in the last century, has been that approving either of these procedures for a few individuals will inevitably lead to overuse and abuse.

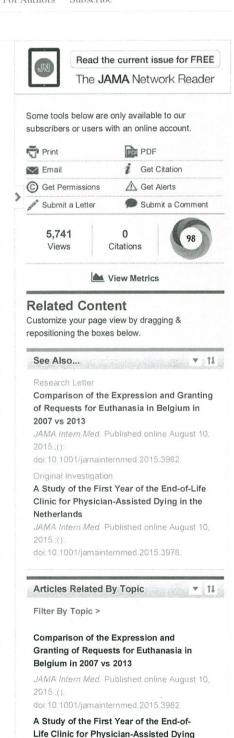
In this issue of JAMA Internal Medicine, Snijdewind et al3 and Dierickx et al4 report recent findings about physician-assisted suicide and euthanasia from the Netherlands and Belgium, respectively. Although neither article mentions the term slippery slope, both studies3-4 report worrisome findings that seem to validate concerns about where these practices might lead. These findings, and other recent data regarding the speeding of patients' deaths,5-8 make this a key moment to revisit efforts in the legalization of assisted dying in the United States and elsewhere, and, specifically, the role of the medical profession.

Snijdewind et al3 report data from the End-of-Life Clinic, an organization established in the Netherlands in 2012 to consider euthanasia or physician-assisted suicide requests from patients whose primary physicians turned down a request or declined to participate. Although not legal, speeding of death is tolerated in the Netherlands for patients with unbearable conditions, without prospect of relief. The End-of-Life Clinic is thus a second opinion for patients who claim this status and who seek aid in dying.

In total, 645 people applied to the clinic during a 1-year period. Physicians approved 162 requests (25.1%), rejected 300 (46.5%), and reached no decision in the remaining cases. Some of the rationales given are reassuring. For example, requests characterized by psychological as opposed to physical suffering were more likely to be rejected, as were requests by individuals who lived alone. Thus, fears were mitigated that solitary, depressed individuals with potentially reversible conditions might successfully end their lives.

However, other findings are very worrisome. Most notably, 6.8% of those who successfully obtained euthanasia or physician-assisted suicide were categorized as tired of living. A total of 3.7% reported only psychological suffering. Although it is possible that such people were suffering unbearably and not apt to improve, the term tired of living is vague and thus disturbing. Similarly, 49.1% of those whose requests were granted characterized part of their suffering as loneliness. Loneliness, even if accompanied by other symptoms, hardly seems a condition best addressed by offering death. Finally, that 53.7% of approved requests are among those 80 years and older raises red flags. Is old age itself being conflated with suffering? Is it possible that there is a not-so-subtle ageism here among the physicians approving such requests?

The validity of these concerns is strengthened by reports that 1 (3.3%) in 30 people in the Netherlands died by euthanasia in 2012, roughly triple the percentage in 2002 when the practice was first decriminalized. According to a recent article in Newsweek, the definition of unbearable suffering in the Netherlands has been expanding every year.6



in the Netherlands

As Dierickx et al<sup>4</sup> report, the rate of euthanasia is also increasing in Belgium where the practice is fully legal (although physician-assisted dying is not officially condoned). Whereas 1.9% of all deaths in Flanders, Belgium, in 2007 were by euthanasia, the percentage increased to 4.6% by 2013; this represents 1 in 22 deaths—even higher than the 1 in 30 deaths in the Netherlands. Their data also indicate that the percentage of euthanasia requests that were approved in Flanders increased from 55% in 2007 to 77% in 2013. As in the Netherlands, there are safeguards in place in Belgium; patients must have constant and unbearable physical or psychological suffering and make repeated, voluntary requests.

In Belgium, physical suffering without prospects of improvement was the most common reason given for granting euthanasia. However, as is the case in the Netherlands, there are worrisome trends. Applicants were allowed to list tiredness of life in their requests in 2013 (but not in 2007), and the fastest-growing populations receiving euthanasia include those potentially vulnerable to discrimination and stigma, such as women, people older than 80 years, those with less educational attainment, and nursing home residents. A June 2015 articles in the *New Yorker* corroborated these concerns, telling the story of a depressed woman who was chatting and laughing on the way to her euthanasia appointment and reporting that other Belgians had been euthanized for such conditions as autism, anorexia, and chronic fatigue syndrome.

Both of these studies are well done but contain gaps. For example, the Netherlands data are limited in that the reported diagnoses were those offered by patients, not those ultimately made by the physicians who said either yes or no. In both studies, there are no descriptions of specific cases, so it is hard to know exactly what the physical and psychological suffering of the individuals in question actually looked like. Similarly, we do not know what those who identified themselves as lonely or tired of living were experiencing. Had they and their physicians exhausted all options that might have restored some of their happiness? Could and should public policy do more for them?

The slippery slope is not always a persuasive argument. However, these data and the other recent reports<sup>5-8</sup> require that it be taken very seriously. On the one hand, some of the trends may be welcome. To the degree that there is unremitting suffering among these patients and physicians at the End-of-Life Clinic and in Flanders are providing expanded access, their efforts may be ethically defensible. On the other hand, though, the increasing rates of euthanasia may alternatively represent a type of reflexive, carte blanche acquiescence among physicians to the concept of patient self-determination. Or worse, is it simply easier for physicians to accede to these sad and alling patients' wishes than to reembark on new efforts to relieve or cope with their suffering? As one Dutch ethics professor has said, "The risk now is that people no longer search for a way to endure their suffering." In other words, are the Netherlands and Belgium turning to physicians to solve with euthanasia what are essentially psychosocial issues? And one additional question: Did physicians in the End-of-Life Clinic diagnose unbearable suffering in patients previously not given that diagnosis because they are better diagnosticians or because the clinic was set up by Right to Die NL, a proeuthanasia organization?

Part of the problem with the slippery slope is you never know when you are on it. Is the use of euthanasia or physician-assisted suicide appropriate for 1 of 20 to 25 dying patients? What if the next round of data indicates that the number has increased to 1 of 10 or 15 patients? Careful, independent studies are crucial to ensure that the safeguards put in place in the Netherlands and Belgium are working and that these end-of-life strategies remain ones of last resort for desperate individuals, not the wrong response to frailty and languages.

The European data are particularly relevant for the United States. Although proven interventions that ease the suffering of dying patients, such as hospice and palliative care, remain underused, 25 state legislatures and the District of Columbia have considered legislation related to physician-assisted dying during 2015. Versions of physician-assisted dying are already allowed by legislation in Oregon, Washington, and Vermont and by court decisions in Montana and New Mexico. A 2014 Gallup poll found that 7 of 10 Americans believe physicians should be allowed to "legally end a patient's life by some painless means." Meanwhile, the Supreme Court of Canada ruled in February 2015 that terminally ill patients in that country have the right to physician-assisted suicide.

Although the euthanasia practices in the Netherlands and Belgium are unlikely to gain a foothold in the United States, a rapidly aging population demanding this type of service should give us pause. Physicians must primarily remain healers. There are numerous groups that are potentially vulnerable to abuses waiting at the end of the slippery slope—the elderly, the disabled, the poor, minorities, and people with psychiatric impairments. When a society does poorly in the alleviation of suffering, it should be careful not to slide into trouble. Instead, it should fix its real problems.

## ARTICLE INFORMATION

A

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Conflict of Interest Disclosures: None reported.

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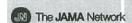
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REVIEW

## Euthanasia and assisted suicide: a physician's and ethicist's perspectives

## | Donald Boudreau<sup>1</sup> Margaret A Somerville<sup>2</sup>

Faculty of Medicine, Department of Medicine, McGill University, Montreal, QC, Canada; <sup>2</sup>Faculty of Law, Faculty of Medicine, and Centre for Medicine, Ethics and Law, McGill University, Montreal, QC, Canada



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Abstract: The debate on legalizing euthanasia and assisted suicide has a broad range of participants including physicians, scholars in ethics and health law, politicians, and the general public. It is conflictual, and despite its importance, participants are often poorly informed or confused. It is essential that health care practitioners are not among the latter. This review responds to the need for an up-to-date and comprehensive survey of salient ethical issues. Written in a narrative style, it is intended to impart basic information and review foundational principles helpful in ethical decision-making in relation to end-of-life medical care. The authors, a physician and an ethicist, provide complementary perspectives. They examine the standard arguments advanced by both proponents and opponents of legalizing euthanasia and note some recent legal developments in the matter. They consider an aspect of the debate often underappreciated; that is, the wider consequences that legalizing euthanasia might have on the medical profession, the institutions of law and medicine, and society as a whole. The line of argument that connects this narrative and supports their rejection of euthanasia is the belief that intentionally inflicting death on another human being is inherently wrong. Even if it were not, the risks and harms of legalizing euthanasia outweigh any benefits. Ethical alternatives to euthanasia are available, or should be, and euthanasia is absolutely incompatible with physicians' primary mandate of healing.

**Keywords:** euthanasia, physician assisted-suicide, healing, suffering, palliative care, palliative sedation

### Introduction

One of us (JDB) was recently attending on a clinical service where a situation arose that prompted a discussion concerning assisted suicide. It revealed a surprising lack of consensus among physicians regarding the difference between assisted suicide and euthanasia, as well as an appalling level of confusion about basic facts. Such a situation is disconcerting, given that good ethical decision-making requires "getting the facts straight" as an essential first step. It may be understandable that personal perspectives will vary on matters such as physician-assisted suicide (PAS) and euthanasia, particularly in our pluralistic societies. However, it is unacceptable that conversations of a professional nature would proceed in the absence of agreement on relevant first principles and without a shared knowledge base. It would be akin to a cadre of interventional cardiologists, equipped with a shaky grasp of the vascular anatomy of the myocardium, debating the merits of an innovative approach to intracoronary stenting.

This article addresses such lacunae in relation to euthanasia and PAS. (We will use the word euthanasia to include PAS except where we state otherwise or it is clear we are dealing with the issues separately). We define euthanasia and assisted suicide, reveal common misconceptions in this regard, and expose euphemisms that, regrettably, often serve to confuse and deceive. We review the main arguments advanced by proponents and opponents of legalizing euthanasia. The philosophical assumptions guiding our perspectives are laid out. We consider the effect of legalization on patients and their families, physicians (as individuals and a collectivity), hospitals, the law, and society at large. Our goal is to provide a vade mecum useful in end-of-life care and ethical decision-making in that context.

## **Definitions**

### Euthanasia

Euthanasia is an emotionally charged word, and definitional confusion has been fermented by characterizations such as passive versus active euthanasia. Some have suggested avoiding using the word altogether.<sup>1,2</sup> We believe it would be a mistake to abandon the word, but we need to clarify it.

The word's etymology is straightforward: eu means good and Thanatos means death. Originally, euthanasia meant the condition of a good, gentle, and easy death. Later, it took on aspects of performativity; that is, helping someone die gently. An 1826 Latin manuscript referred to medical euthanasia as the "skillful alleviation of suffering", in which the physician was expected to provide conditions that would facilitate a gentle death but "least of all should he be permitted, prompted either by other people's request or his own sense of mercy, to end the patient's pitiful condition by purposefully and deliberately hastening death".3 This understanding of euthanasia is closely mirrored in the philosophy and practice of contemporary palliative care. Its practitioners have strongly rejected euthanasia.4

Recently, the noun has morphed into the transitive verb "to euthanize". The sense in which physicians encounter it today, as a request for the active and intentional hastening of a patient's demise, is a modern phenomenon; the first sample sentence given by the Oxford English Dictionary to illustrate the use of the verb is dated 1975.5 The notion of inducing, causing, or delivering a (good) death, so thoroughly ensconced in our contemporary, so-called "progressive values" cultural ethos, is a new reality. That fact should raise the question: "Why now?" The causes go well beyond responding to the suffering person who seeks euthanasia, are broad and varied, and result from major institutional and societal changes.<sup>6</sup>

Physicians need a clear definition of euthanasia. We recommend the one used by the Canadian Senate in its 1995 report: "The deliberate act undertaken by one person

with the intention of ending the life of another person in order to relieve that person's suffering."<sup>7</sup>

Terms such as active and passive euthanasia should be banished from our vocabulary. An action either is or is not euthanasia, and these qualifying adjectives only serve to confuse. When a patient has given informed consent to a lethal injection, the term "voluntary euthanasia" is often used; when they have not done so, it is characterized as "involuntary euthanasia". As our discussion of "slippery slopes" later explains, jurisdictions that start by restricting legalized euthanasia to its voluntary form find that it expands into the involuntary procedure, whether through legalizing the latter or because of abuse of the permitted procedure.

In the Netherlands, Belgium, and Lichtenstein, physicians are legally authorized, subject to certain conditions, to administer euthanasia. For the sake of clarity, we note here that outside those jurisdictions, for a physician to administer euthanasia would be first-degree murder, whether or not the patient had consented to it.

### Assisted suicide

Assisted suicide has the same goal as euthanasia: causing the death of a person. The distinction resides in how that end is achieved. In PAS, a physician, at the request of a competent patient, prescribes a lethal quantity of medication, intending that the patient will use the chemicals to commit suicide. In short, in assisted suicide, the person takes the death-inducing product; in euthanasia, another individual administers it. Both are selfwilled deaths. The former is self-willed and self-inflicted; the latter is self-willed and other-inflicted. Although the means vary, the intention to cause death is present in both cases.

Some will argue that agency is different in assisted suicide and euthanasia; in the former, the physician is somewhat removed from the actual act. To further this goal, two ethicists from Harvard Medical School in Boston, Massachusetts, USA, have proposed strategies for limiting physician involvement in an active death-causing role.8 It is, indeed, the case that patients provided with the necessary medication have ultimate control over if, when, and how to proceed to use it; they may change their mind and never resort to employing it. However, in prescribing the means to commit suicide, the physician's complicity in causing death is still present. There are, however, some limits on that complicity, even in the jurisdictions where it has been legalized. For instance, even supporters of PAS in those jurisdictions agree it is unethical for physicians to raise the topic with individuals, as that might constitute subtle coercion or undue influence, whether or not intended.

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PAS has been decriminalized in Oregon, Washington State, Montana, and Vermont, and absent a "selfish motive", assisted suicide is not a crime in Switzerland. Even in these jurisdictions, however, one cannot legitimately speak of a "right" to suicide because no person has the obligation to assist in the suicide. Rather, assisting suicide has been decriminalized for physicians in the American states listed and for any person in Switzerland; that is, it is not a criminal offence for those who comply with the applicable laws and regulations.

## Terminal sedation and palliative sedation

A lethal injection can be classified as "fast euthanasia". Deeply sedating the patient and withholding food and fluids, with the primary intention of causing death, is "slow euthanasia". The use of "deep sedation" at the end of life has become a more common practice in the last decade and has been the focus of controversy and conflict, especially because of its probable abuse.

Certain terminology, such as "palliative terminal sedation", creates confusion between sedation that is not euthanasia and sedation that is euthanasia. It was used, for example, by the Quebec Legislative Assembly in drafting a bill to legalize euthanasia. 10 We note that creating such confusion might constitute an intentional strategy to promote the legalization of euthanasia. In the amended bill, the term "palliative terminal sedation" was replaced by "continuous palliative sedation", which the patient must be told is irreversible, clearly indicating the legislature's intention to authorize "slow euthanasia", although many people might not understand that is what it means. The bill died on the order paper when a provincial election was called before it was passed. Immediately after the election the bill was reintroduced at third reading stage by unanimous consent of all parties and passed by a large majority. This new law allowing euthanasia in Quebec, the only jurisdiction in North America to do so, remains the focus of intense disagreement and is now being challenged as ultra vires the constitutional jurisdiction of Quebec.

"Palliative sedation", which is relatively rarely indicated as an appropriate medical treatment for dying people, is used when it is the only reasonable way to control pain and suffering and is given with that intention. It is not euthanasia. "Terminal sedation" refers to a situation in which the patient's death is not imminent and the patient is sedated with the primary intention of precipitating their death. This is euthanasia. The terms palliative terminal sedation and continuous palliative sedation confound these two ethically and legally different situations.

Euthanasia advocates have been arguing that we cannot distinguish the intention with which these interventions are undertaken, and therefore, this distinction is unworkable. But the circumstances in which such an intervention is used and its precise nature allow us to do so. For instance, if a patient's symptoms can be controlled without sedation, yet they are sedated, and especially if the patient is not otherwise dying and food and fluids are withheld with the intention of causing death, this is clearly euthanasia. Needing to discern the intention with which an act is carried out is not unusual. For instance, because intention is central to determining culpability in criminal law, judges must do so on a daily basis. We note, also, that intention is often central in determining the ethical and moral acceptability of conduct, in general.

Within the realm of decision-making in a medical context, withdrawal of artificial hydration and nutrition has continued to be a very contentious issue in situations in which persons are not competent to decide for themselves about continuing or withdrawing this treatment. The questions raised include: When does its withdrawal constitute allowing a person to die as the natural outcome of their disease (when it is not euthanasia)? And when does its withdrawal constitute starving and dehydrating a person to death (when it is euthanasia)?

## Our key assumptions

In discussing an issue as contentious as euthanasia, which has a foundational base in values as well as facts and knowledge, it is incumbent on us to identify our underlying philosophical beliefs and assumptions. This will orient the reader to the line of logic that links the ensuing arguments.

People undertaking an ethical analysis belong in one or other of two main camps: principle-based (or deontological) ethics or utilitarian ethics. We belong to the first group. We believe there exists a universal morality and that, at the very least, there is significant intercultural agreement on core concepts of ethics. It is important to recognize that agreement when it exists, because we should try to start our ethical debates from where we agree, not from our disagreements. Doing so allows an experience of a shared morality, which gives a different tone to both the debate and our disagreements.

It is beyond the scope of this article to discuss in depth the putative origins of this human moral sense. For religious people, it is to be found in their religious beliefs. Perhaps it is a result of Darwinian natural selection and has come to be written in our genetic code and reflected in our common neurobiological apparatus. Perhaps it is a product of the powerful reasoning capabilities of *Homo sapiens*, culminating in a rationalization process that recognizes the survival and other

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advantages of cultivating virtues such as altruism and fairness over greed and injustice. Perhaps its origins will forever elude us and we must be content with describing it through concepts such as moral intuition. Perhaps it is some combination of all of these factors and others. Regardless, it has often been said that even in secular societies, close to 100% of its citizens adhere to moral codes, whether implicit (eg, the ethical "yuck" factor) or explicit (eg, the Ten Commandments).

As a consequence, we endorse the view that the practice of medicine is necessarily constrained by moral absolutes. In other words, we categorically reject moral relativism, the utilitarian view that what is right or wrong depends just on weighing whether benefits outweigh risks and harms, and in particular, that this is only a matter of personal judgment. Some things ought never to be done to patients by their physicians. In relation to euthanasia, physician—philosopher Edmund Pellegrino states it well: "Physicians must never kill. Nothing is more fundamental or uncompromising". We strongly agree, and this central tenet informs our entire line of argument.

We believe that future generations looking back on the twenty-first century euthanasia debate (which is taking place in most Western democracies) will see it as the major values debate of the century and determinative of the most important foundational values of the world they will have inherited.

## Basic concepts related to euthanasia and PAS

## The right to die

The "right to die" terminology is used in the euthanasia debate to propose there is a right to have death inflicted. Death is inherent to the human body, vulnerable and inexorably aging; death can be accelerated or temporarily delayed, but never thwarted. The inevitability of death is an explicit, necessary, noncontingent, and universalizable phenomenon true for all living beings. There is no "right to die". In contradistinction, there are fundamental human rights to "life, liberty and security of the person".

Where there is a right, there is an obligation; therefore, were a "right to die" to exist, a logical consequence would be that some other person or agent would have a duty to inflict death (especially if the requisitioner were physically incapable of accomplishing the act themselves). Pro-euthanasia advocates rely heavily on this line of logic and have used it to impose responsibility for carrying out euthanasia onto the medical profession.

The claim to a right to die must be distinguished from a "right to be allowed to die"; for instance, by refusing life-support treatment. The right to permit the dying process

to unfold unimpeded flows from and is a consequence of persons' exercise of their right to inviolability, the right not to be touched without their informed consent. It does not establish any right to die in the sense of a "right to be killed".

A recent case from British Columbia, Carter v. Canada (Attorney General), 12 illustrates the arguments that emerge between those arguing for a right to die (legalized euthanasia) and those opposing it. Gloria Taylor, a woman with amyotrophic lateral sclerosis who was one of the plaintiffs, challenged the constitutional validity of the prohibition on assisted suicide in the Canadian Criminal Code. 13 Suicide and attempted suicide used to be crimes under the code, but these crimes were repealed by the Canadian Parliament in 1972. However, the crime of assisting suicide was not repealed. The trial judge in the Carter case, Justice Lynn Smith, considered the reasons for that repeal. She accepted that it was not done to give a personal choice to die priority over "the state interest in protecting the lives of citizens; rather, it was to recognize that attempted suicide did not mandate a legal remedy". 12 With respect, we propose an alternative explanation: The designation of those acts as crimes was abolished to try to save the lives of suicidal people. It was hoped that if society removed the threat of possibly being charged with a criminal offence, they and their families would be more likely to seek medical assistance.

In coming to her conclusions that PAS can be ethically acceptable and ought to be legally allowed in certain circumstances, Justice Smith relied heavily on the fact that it is no longer a crime to commit or attempt to commit suicide and asked, why, then, is it a crime to assist it? "What is the difference between suicide and assisted suicide that justifies making the one lawful and the other a crime, that justifies allowing some this choice, while denying it to others?" 12

The answer is that decriminalizing suicide and attempted suicide is intended to protect life; decriminalizing assisted suicide does the opposite. As explained earlier, intentions are often central in deciding what is and is not ethical.

Society tries to prevent suicide. Notwithstanding the influence of pro-euthanasia advocates, the preponderant societal view is that suicide, at least outside the context of terminal illness, must not be tolerated. Suicide is generally considered a failure of sorts: the manifestation of inadequately treated depression, a lapse in community support, a personal short-coming, societal disgrace, or a combination thereof. Even if in certain societies in ancient times suicide was not illegal, it was generally frowned upon.<sup>14</sup>

Importantly, the decriminalization of suicide does not establish any right to die by suicide. Furthermore, if there were such a right, we would have a duty not to treat people Dovepress Euthan Stal Davis Stal

who attempt suicide. In other words, if there were a right to choose suicide, it would mean that we have correlative obligations (perhaps subject to certain conditions such as ensuring the absence of coercion) not to prevent people from making that choice. Hospital emergency rooms and health care professionals faced with a patient who has attempted suicide do not, at present, act on that basis. Psychiatrists who fail to take reasonable care that their patients do not commit suicide, including by failing to order their involuntary hospitalization to prevent them committing suicide, when a reasonably careful psychiatrist would not have failed to do so, can be liable for medical malpractice, unprofessional conduct, and even, in extreme cases, criminal negligence.

Another distinguishing feature between suicide and assisted suicide must be underlined. Suicide is a solitary act carried out by an individual (usually in despair). PAS is a social act in which medical personnel licensed and compensated by society are involved in the termination of the life of a person. It asks not that we attempt to preserve life, the normal role of medicine and the state, but that we accept and act communally on a person's judgment that his or her life is unworthy of continuance. (We are indebted to Canadian bioethicist Dr Tom Koch for this particular formulation of the issue.)

## Autonomy

Advocates of euthanasia rely heavily on giving priority to the value of respect for individuals' rights to autonomy and selfdetermination. Respect for autonomy is the first requirement listed in the principlism approach to biomedical ethics, known as the "Georgetown mantra", which strongly influenced the early development of applied ethics in the 1980s.<sup>15</sup> It refers to a person's right to self-determination, to the inherent right of individuals to make decisions based on their constructions of what is good and right for themselves. The autonomous personal self is seen to rule supreme. It washes over the relational self, the self that is in connection with others in the family and community. Autonomy is often treated as an "uber" right trumping all other rights. It renders moot many obligations, commitments, and considerations beyond the risks, harms, and benefits to the individual involved. The inclination to attribute primary importance to autonomy may be alluring at first glance; clearly, no physician educated in today's ethical zeitgeist (patient-centered, partnershipseeking, and consent-venerating) would want to be seen to be violating someone's autonomy by disrespecting their right to make personal choices. That would smack of paternalism or authoritarianism, which are seen by "progressives" as heinous wrongs.

The way in which respect for autonomy is implemented in practice and in law is through the doctrine of informed consent. Among many requirements, it demands that the patient be fully informed of all risks, harms, benefits, and potential benefits of the proposed procedure and its reasonable alternatives. As a consequence, to obtain legally valid informed consent to euthanasia, the patient must be offered fully adequate palliative care. As well, the patient must be legally and factually mentally competent, and their consent must be voluntary: free of coercion, duress, or undue influence. We question whether these conditions can be fulfilled, at least with respect to many terminally ill patients.

## Individual autonomy and perspectives from the individual's family

It is useful to consider the historical roots of individual autonomy and its possible links to the movement to legalize euthanasia. The belief that one has the right to die at the time, place, and in the conditions of one's choosing is based on the conviction that one owns one's body and that one can do with it as one pleases. It is an idea deeply rooted in the humanist worldview.

The notion of a personal self emerged in the Renaissance, where it was thought that the personal self could be worked on and perfected. It was quite distinct from more ancient concepts of humans as part of a greater and unified whole. Pica della Mirandola (quoted in Proctor 1988)<sup>16</sup> captures the sentiment: "We have made thee neither of heaven nor of earth, neither mortal nor immortal, so that with freedom of choice and with honor, as though the maker and molder of thyself, thou mayest fashion thyself in whatever shape thou shalt prefer." It does not require a huge conceptual leap to appreciate that if the self can be created, the process should be reversible: self-making balanced with self-annihilation. Self-determinationism is a type of solipsism discernible at the very core of most philosophical arguments in favor of euthanasia.

The concept of autonomy can be problematized. It is, as ethicist Alfred Tauber has suggested, two-faced. <sup>17</sup> He describes two conceptions of autonomy: one that is dependent on radical self-direction and human separateness and another that is other-entwined and constitutive of social identities. He places interdependence, interpersonal responsibility, and mutual trust as counterpoints to free choice. He argues that both are necessary for society to thrive and for medicine to fulfill its moral imperative. Autonomy is also being rethought by some feminist scholars through a concept called "relational autonomy". <sup>18</sup> This recognizes that, hermits

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aside, we do not live as solitary individuals but, rather, in a web of relationships that influence our decisions, and that these must be taken into account in assessing whether or not our decisions are autonomous. The role that respect for autonomy should play in relation to the decision whether to legalize euthanasia must be examined not only from the perspective of the patient but also from the perspective of the patient's relations. In the current debate, the latter have often been neglected.

It is ethically necessary to consider the effects on a person's loved ones of that person's decision to request euthanasia. We illustrate this by making reference to the BBC television program "Coronation Street", the longestrunning television soap opera in history. It recently focused on a character named Hayley Cropper. In a series of episodes in early 2014, Hayley was diagnosed with pancreatic cancer and subsequently resorted to suicide in the presence of her husband, Roy Cropper. The producers of the show succeeded in plucking at heart strings and eliciting empathic responses from the audience. The character had a complex personal narrative that permitted one to appreciate why she might have wanted to hasten her own death: she was a transsexual woman who feared reverting to her previous male identity as her dying process progressed. The producers, always attuned to contemporary societal issues, made sure to balance Hayley's suffering with a reciprocal harm, wrought on her husband Roy and another character, Fiona (Fiz) Brown. Roy became tormented with guilt by association, and Fiz was seriously traumatized because she was deprived of the opportunity to say goodbye to Hayley, her foster mother. The point made was that self-willed death may be merciful to oneself and simultaneously cruel to others. There is an essential reciprocity in human life. We are neither islands in the seas nor autonomous, self-sufficient planets in the skies.

We must also examine the effect of legalizing euthanasia from the perspective of physicians' and other health care professionals' autonomy with respect to freedom of conscience and belief, and the effect it would have on institutions and society as a whole. The overwhelming thrust of the euthanasia debate in the public square has been at the level of individual persons who desire euthanasia. Although that perspective is an essential consideration, it is not sufficient. Even if euthanasia could be justified at the level of an individual person who wants it (a stance with which we do not agree), the harm it would do to the institutions of medicine and law and to important societal values, not just in the present but in the future, when euthanasia might become the norm, means it cannot be justified.

Loss of autonomy, experienced or anticipated, is one of the reasons that might prompt a patient to request death from their physician. Other reasons include pain, but it is not the most important. Thankfully, modern medicine is, with few exceptions, effective at relieving physical symptoms, particularly pain. These other sources of suffering are largely in the psychosocial domain, as the recent annual report by Oregon's Public Health Division (released on January 28, 2014) demonstrates. During a 14-year period (1998-2012), the three most frequently mentioned end-of-life concerns were loss of autonomy (91.4%), decreasing ability to participate in activities that made life enjoyable (88.9%), and loss of dignity (80.9%). 19 A loss in bodily function is linked to the fear of becoming a burden on loved ones and is often experienced as an assault on human dignity. It is important to note that depression can represent either an indication or a contraindication for euthanasia. A list of end-of-life concerns that can be linked to requesting euthanasia is presented in Table 1.

We turn now to another critically important value, respect for life, which, in the context of euthanasia, is in conflict with respect for autonomy. In discussing euthanasia, the one cannot be properly considered in isolation from the other.

## Respect for human life

Respect for human life must be maintained at two levels: respect for each individual human life and respect for human life in general. Even if it were correct, as pro-euthanasia advocates argue, that when a competent adult person gives

Table I List of common reasons for requested death

#### Reasor

Loss of autonomy and independence (eg, loss of control over decisions, inability to make decisions, loss of self-care abilities)

Less able to engage in activities making life enjoyable

Perceived loss of human dignity; this is often related to an impairment of physiological functions in basic body systems (eg, bowel functioning, swallowing, speech, reproduction) or preoccupations with bodily appearance

A fear of becoming a burden on family, friends, and community Cognitive impairment or fear of cognitive impairment Depression, hopelessness (nothing to look forward to), or demoralization\*

Feeling useless, unwanted, or unloved; social isolation Inadequate pain control or concern about it

Existentialist angst or terror, mortality salience, fear of the unknown Intractable symptoms other than pain (eg, pruritus, seizures,

paresthesias, nausea, dyspnea)

Financial implications of treatment

**Notes:** This list is not presented in the order of frequency. \*Some experts deny that demoralization actually exists as a mental disorder separate from clinical depression.

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informed consent to euthanasia there is no breach of respect for human life at the level of the individual, there is still a breach of respect for human life in general. If euthanasia is involved, how one person dies affects more than just that person; it affects how we all will die.

Respect for life is implemented through establishing a right to life. We return to the trial judgment in the Carter case because it illustrates how such a right can be distorted and co-opted in the service of legalizing PAS or even euthanasia. In applying the right to life in section 7 of the Canadian Charter of Rights and Freedoms<sup>20</sup> to Ms Taylor's situation, Justice Smith says:

[T]he [Criminal Code] legislation [prohibiting assisted suicide] affects her right to life because it may shorten her life. Ms Taylor's reduced lifespan would occur if she concludes that she needs to take her own life while she is still physically able to do so, at an earlier date than she would find necessary if she could be assisted.12

What is astonishing is the novel, to say the least, way in which Justice Smith constructs a breach of Ms Taylor's Charter right to life. In effect, Justice Smith's reasoning converts the right to life to a right to death by PAS or euthanasia. Justice Smith's judgment was overturned by a two to one majority in the British Columbia Court of Appeal, as contrary to a Supreme Court of Canada precedent ruling that the prohibition of assisted suicide is constitutionally valid.<sup>21</sup> It is now on appeal to the Supreme Court of Canada; we note its liberty to override its previous precedents.

## Obfuscations and the main arguments of proponents and opponents

Proponents of euthanasia often use rhetorical devices to foster agreement with their stance by making it more palatable. One of these is to eliminate the use of words that have a negative emotional valance. As mentioned previously, "suicide" has been a taboo for many cultures and across time. Some commentators have described concepts such as suicide clusters, suicidal contagion, and suicide scripting; none of these are considered beneficial to society. As a consequence, there have been efforts at replacing the terminology of assisted suicide with assisted dying. A former editor of the New England Journal of Medicine, Marcia Angell, has stated that the latter expression is more appropriate because it describes someone "who is near death from natural causes anyway while the former refers to something occurring in someone with a normal life expectancy". 22 We doubt that she was actually meaning to imply that human lives have less intrinsic worth

as persons approach death; however, that interpretation is logical and inevitable.

Another strategy to whitewash "death talk" is to figuratively wrap it within the white coat of medicine. Cloaking these acts in medical terms softens them and confers legitimacy. This has spawned a host of euphemisms such as "medically assisted death", "medical-aid-in-dying", and "death with dignity". After all, we all want good medical care when we are dying. A strategy that may escape scrutiny is to link assisted suicide with physicians; that is, PAS. However, assisted suicide and euthanasia are not necessarily glued to physicians. Nurses could perform these procedures, although most recoil at the prospect. In theory, almost anyone (ambulance drivers, veterinarians, pharmacists, lawyers) could be empowered and trained to euthanize. We have argued elsewhere that if society is going to legalize euthanasia (which we oppose it doing), it could equip itself with a new occupation of euthanology,<sup>23</sup> thereby relieving physicians of having to contravene their ancient guiding principle of primum non nocere.

One must also be wary of euphemisms because they dull our moral intuitions and emotional responses that warn us of unethical conduct. In our world of desktops, laptops, and smartphones, where one's existence is proclaimed and validated on computer screens and intersubjectivity is channelled in cyberspace, we would not be surprised to see some enterprising euthanologist of the future advertise a gentle "logging-off". Although fanciful, this prediction is well aligned with a conception of the world that views persons as reducible to bodies with complex networks of neurological circuits wherein the entire range of human experiences can be created, recorded, interpreted, and terminated.

This conception of human existence can also breed rather extreme points of view, such as the one that considers the failing body as "unwanted life support". David Shaw has suggested that, "if a patient is mentally competent and wants to die, his body itself constitutes unwarranted life support unfairly prolonging his or her mental life".24

Many current attitudes and values could affect how terminally ill, dying, and vulnerable people are treated. For example, if materialism and consumerism are priority values, euthanasia fits with the idea that, as one pro-euthanasia Australian politician put it: "When you are past your 'use by' or 'best before' date, you should be checked out as quickly, cheaply and efficiently as possible." But we are not products to be checked out of the supermarket of life. As this shows, some who advocate in favor of euthanasia resort to intense reductionism in buttressing their arguments. If one thinks of

Medicolegal and Bioethics 2014:4 7 a human being as having an essence comprised of more than bodily tissues, then the intellectual, emotional, and social barriers to euthanasia come to the fore.

Euphemizing euthanasia through choice of language is not the only "legalizing euthanasia through confusion" strategy. <sup>25</sup> Another is the "no difference" argument. The reasoning goes as follows: refusals of treatment that result in a shortening of the patient's life are ethical and legal; this is tantamount to recognizing a right to die. Euthanasia is no different from them, and it's just another way to implement the right to die. Therefore, if we are to act consistently, that too should be seen as ethical and legal. The further, related, argument is that euthanasia is simply another form of medical treatment. However, as explained previously, the right to refuse treatment is not based on a right to die, and both the intention of the physician and the causation of death are radically different in those cases compared with euthanasia.

The main arguments in favor of and in opposition to euthanasia are presented in Table 2. Prominent on the yea side are the autonomy principle and the belief that putting an end to suffering through euthanasia is merciful and justifies euthanasia. Prominent on the nay side are the corrosive

 Table 2 Main arguments advanced by proponents and opponents

 of euthanasia

#### **Arguments**

Arguments in favor of euthanasia

Persons have an inalienable right to self-determination; that is, patients can decide how, where, and when they are going to die. Euthanasia is a profoundly humane, merciful, and noble humanitarian gesture because it relieves suffering.

Assistance in dying is a logical and reasonable extension to end-of-life care and involves only an incremental expansion of practices that are legal and seen as ethical.

It bypasses physicians' reluctance to accept patients' advanced directives and their requests to limit interventions.

It can be carried out humanely and effectively, with negligible risk of slippery slopes.

#### Arguments against euthanasia

Intentionally taking a human life, other than to save innocent human life, is inherently wrong and a violation of a universal moral code.

The value of respect for autonomy must be balanced by other values, particularly respect for individual human life and respect for human life in general.

It is different in kind from other palliative care interventions aimed at relieving suffering, such as pain management, and from respect for patients' refusals of life support treatment.

Slippery slopes are unavoidable.

It introduces an unacceptable potential for miscommunication within the doctor–patient relationship.

It is incompatible with the role of the physician as healer and would erode the character of the hospital as a safe refuge.

consequences for upholding society's respect for life, the risks of abuse of vulnerable people, and the corruption of the physician's role in the healing process.

## The role of the physician: "doctor as healer"

An absolute barrier to physicians becoming involved with acts that intentionally inflict death is that doing so would be incompatible with their healer role. This statement requires unpacking. The concept of "healing" is a challenging one to define, and it is nearly impossible to explain it in reductionist and objectivist terms. By its very nature, healing is holistic and intersubjective. Balfour Mount, the physician who created the first palliative care unit in North America, has defined it as "a relational process involving movement towards an experience of integrity and wholeness". 26 Such a description does not entirely clarify the situation; Dr Mount once admitted: "When I try to explain what is healing I invariably end up invoking notions such as 'wholeness' or 'soul' and, in the process, I often lose the attention of my colleagues who have been enculturated in the positivist paradigm of scientific methodology." A formulation that may provide a more robust understanding of medicine's healing mandate is the notion that healing amounts to caring for the whole person.

The historical roots that link medicine to healing run deep. In ancient times, a physician's training was represented as an initiation into sacred rites: Asclepius was the healing god. Healers have existed across time and cultures; this is an important focus of interest for medical anthropologists. The Old French and Anglo-Norman word "fisicien" derives from "fisique", which denoted a practitioner of the art of healing. Healing is inseparable from the need of humans to cope with the bafflement, fear, and suffering brought on by sickness. The problems of sickness, accidents, unjustness, and evil are all central concerns of professions with a pastoral function: the ministry and medicine.

Some physicians may attempt to distance themselves and their clinical method from any priestly role and religion as a whole. That resistance is understandable to some extent. However, it has been argued that physicians, by the nature of the clinical encounter, even if they are not necessarily metaphorical shepherds tending their sheep, cannot be considered to be morally neutral technicians.<sup>27</sup> A fascinating commentary on this aspect of medicine comes from an unexpected source. The renowned Canadian novelist Robertson Davies, a self-declared expert on magic, in

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describing the characteristics of a physician, once stated to a medical audience at Johns Hopkins University:

[...] to the wretch who sits in the chair on the other side of your desk. You look like a god [...] the detection and identification of gods in modern life is mine, and I assure you that you look like a god.28

We are not trying to suggest that physicians are priests, let alone gods; we are merely pointing out that, whether or not we are religious, the healing function requires attention to notions of transcendence, and if they have them, patients' theistic beliefs and their spiritual life. Not surprisingly, indeed insightfully, healing has been described as the relief of "soul sickness". 29 The late Dame Cicely Saunders, founder of the modern hospice movement, has equated it to recognizing, reaching, and alleviating "soul pain". Although it is beyond the scope of this article to consider the full breadth of healing as a human phenomenon, a few additional points are in order.

Healing is a journey, rather than a destination, and it is a process more than an epiphany. Recent work by Mount and his collaborators has attempted to characterize healing by contrasting it with wounding. On a quality-of-life continuum, being in a healed state is at a pole marked by an experience of wholeness and personal integrity. Being wounded is situated at the opposite pole and represents an experience of suffering and anguish. Healing is associated with the following perspectives: a sense of connection to self, others, and a phenomenal world (ie, a world experienced through the senses); an ability to derive meaning in the context of suffering; a capacity to find peace in the present moment; a nonadversarial connection to the disease process; and the ability to relinquish the need for control. Wounding is a movement in opposite directions. Suffering is fundamentally a sense of one's own disintegration, of loss of control to prevent that, and an experience of meaninglessness.<sup>30</sup> By counteracting those perceptions, a person can be helped on a healing trajectory, even as death approaches. Healing interventions are always possible. One can die healed. As a consequence, the phrase, "There is nothing more that I can do for you," has no place in medicine.

What does healing look like at the bedside? The following characteristics are frequently emphasized. Healing requires recognizing, listening to, and responding to a patient's story, especially listening for trauma, shame, suffering, lament, and listening in a way that generates "earned trust": "Trust me because I will show that you can trust me." It occurs in the moment, in the present tense, in a series of "nows". There needs to be a profound recognition of and an attempt to mitigate the power differential. There is a duty to nurture

hope, a deep sort of hope, and one that is understood as "having agency to discover meaning".31 Hope has been described as "the oxygen of the human spirit. Without it, our spirit dies. With it we can overcome even seemingly insurmountable obstacles."32

## Alternatives to euthanasia

There are two great traditions in medicine: the prolongation of life and the relief of suffering. The concept of suffering, the fact that it is an affliction of whole persons, rather than bodies only, was explicated several decades ago by the American physician Eric Cassel in his seminal paper: "The Nature of Suffering and the Goals of Medicine."33 This understanding represents one of the central tenets of palliative care medicine. The provision of high-quality care by individuals who share in this belief and are able to act to address the full range of human suffering is the most important goal with respect to terminally ill patients. It also constitutes the obvious and necessary alternative to euthanasia.

A specific approach to palliative care, with conceptual anchors in the concept of healing, has recently been described and used by Canadian psychiatrist Harvey Max Chochinov and colleagues; it is called "dignity therapy".<sup>34</sup> Although we prefer the original term, "dignity-conserving care", because it implies somewhat more modest goals and suggests less of a transfer of agency from patient to physician, this approach holds great promise for assisting patients at the end of life. It provides an entry for a deep exploration of dignity: How does the individual patient conceive of it? How is it threatened? How does it link to vulnerability or a sense of "control"? Where does one get the idea that we are ever in control? It is focused on issues such as "intimate dependencies" (eg, eating, bathing, and toileting) and "role preservation". Chochinov has described one's social roles and their associated responsibilities as "the bricks and mortar" of self.<sup>34</sup> The therapeutic approach described aims to preserve persons' inherent dignity, in part by helping them to see that their intimate dependencies can be attended to without their losing self-respect and that they can continue to play meaningful roles.

## Consequences

A major disagreement between euthanasia advocates and opponents revolves around the existence of slippery slopes. There are two types: the logical slippery slope, the extension of the circumstances in which euthanasia may be legally used, and the practical slippery slope, its abuse (see Table 3). The evidence during the last decade demonstrates that neither slope can be avoided. 35,36 For example, although access to

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euthanasia in the Netherlands has never required people to be terminally ill, since its introduction it has been extended to include people with mental, but not physical, illness, as well as to newborns with disabilities and older children. In Belgium, euthanasia has recently been extended to children, it is being considered whether to do the same for people with dementia, and organs are being taken from euthanized people for transplantation.<sup>37</sup> The logical and practical slippery slopes are unavoidable because once we cross the clear line that we must not intentionally kill another human being, there is no logical stopping point.

When euthanasia is first legalized, the usual justification for stepping over the "do not kill" line is a conjunctive one composed of respect for individual autonomy and the relief of suffering. This justification is taken as both necessary and sufficient for euthanasia. But as people and physicians become accustomed to euthanasia, the question arises, "Why not just relief of suffering or respect for autonomy alone?" and they become alternative justifications.

As a lone justification, relief of suffering allows euthanasia of those unable to consent for themselves according to this reasoning: If allowing euthanasia is to do good to those mentally competent people who suffer, denying it to suffering people unable to consent for themselves is wrong; it is discriminating against them on the basis of mental handicap. So, suffering people with dementia or newborns with disabilities should have access to euthanasia.

If one owns one's own life, and no one else has the right to interfere with what one decides for oneself in that regard

**Table 3** Slippery slopes

## Slopes

The practical slippery slope

Performing euthanasia without informed consent or any consent Persons administering euthanasia who are not legally authorized to do so Failure of reporting euthanasia or physician assisted suicide as required

Misclassifying euthanasia as "palliative sedation"

Noncompliance with safeguard protocols (eg, not obtaining psychiatric evaluations of competence, circumventing policies for mandatory second opinions, functioning as "willing providers" without having had a previous clinical relationship with the patient)

The logical slippery slope

Euthanasia offered to those with existentialist angst, mental illness, anorexia nervosa, depression

Euthanasia expanded to include patients with dementia

Euthanasia expanded to persons who are neither physically nor mentally ill: "over 70 and tired of life"

Extending legislation to include children

Euthanasia becomes accepted as medical care, as a sort of

"therapeutic homicide"

(as pro-euthanasia advocates claim), then respect for the person's autonomy as a sufficient justification means that the person need not be suffering to access euthanasia. That approach is manifested in the proposal in the Netherlands that euthanasia should be available to those "over 70 and tired of life".<sup>38</sup>

Once the initial justification for euthanasia is expanded, the question arises, "Why not some other justification, for instance, saving on health care costs, especially with an aging population?" Now, in stark contrast to the past when saving health care costs through euthanasia was unspeakable, it is a consideration being raised.

Familiarity with inflicting death causes us to lose the awesomeness of what euthanasia entails; namely, inflicting death. The same is true in making euthanasia a medical act. And both familiarity with inflicting death and making euthanasia a medical act make its extension, and probably abuse, much more likely, indeed, we believe inevitable, were it to be legalized. We need to stay firmly behind the clear line that establishes that we must not intentionally kill one another.

Those most at risk from the abuse of euthanasia are vulnerable people: those who are old and frail or people with mental or physical disabilities. We have obligations to protect them, and euthanasia does the opposite, it places them in danger. We need, also, to consider the cumulative effect of how we treat vulnerable people. What would be the effect of that on the shared values that bind us as a society and in setting its "ethical tone"? As one of us (MAS) has repeatedly pointed out, we should not judge the ethical tone of a society by how it treats its strongest, most privileged, most powerful members, but rather by how it treats its weakest, most vulnerable and most in need. Dying people belong to the latter group.

Among the most dangerous aspects of legalizing euthanasia are the unintended boomerang effects it will have on the medical profession. The concept of "unanticipated consequences of purposive social action" is a well-described phenomenon in sociology. In his classic paper, American sociologist Robert Merton distinguishes between the consequences of purposive actions that are exclusively the result of the action and those, unpredictable and often unintended, that are mediated by social structures, changing conditions, chance, and error. For example, with respect to euthanasia, there is really no guarantee that the legal and administrative policies erected today, even if currently they functioned as intended, which is doubtful, will be as effective in a different cultural context decades hence.

Then there are the insidious changes induced by the force of habit: the unexamined and autonomic modes of

human behavior. How will the legitimatization of euthanasia and its insertion in the everyday professional vernacular and practice alter the ethos of medicine? The risks are of a grave nature and are immeasurable. How will the involvement of physicians in inflicting death affect their thinking, decisions, and day-to-day practice? Given that euthanasia may be routinized and expedient, there is a distinct possibility that death will become trivialized and that avenues for dignity-preserving care will remain unexplored. What are the potential corrosive effects on hospitals of accepting the language of euthanasia and in implementing that mandate? The language we use not only reflects reality but constructs reality. As German philosopher Martin Heidegger has said, "Language is the house of Being. In its home man dwells". 40 One can imagine that "H", currently a symbol of hospice and hope, will become conflated with an "H" that stands for hollowness and hastened death. We have little doubt that the slippery slopes include a language of abandonment, generating medical practices that will vitiate hope, and a profession that will struggle to identify a true north on its moral compass.

## **Conclusion**

We have introduced an ethical issue that is frequently overlooked in the euthanasia debate: the effects and unintended consequences of legalizing it on the medical profession and on the institutions of law and medicine. Religion used to be the principal carrier of the value of respect for life for society, but in secular societies, that role has fallen to law and medicine, which are "value-creating, value-carrying and consensus-forming for society as a whole".<sup>41</sup> The law prohibits killing another person, and physicians take an oath not to inflict death. These imperatives must never be abrogated, which legalizing euthanasia, accepting the notion of "therapeutic homicide",<sup>42</sup> would necessarily do.

This article is the product of two individuals who bring complementary modes of thinking to the issues raised by euthanasia. One (JDB), a specialist physician, has developed his practical knowledge from years of accompanying patients throughout the trajectory of illness, including at the end of life. The other (MAS), an ethicist and lawyer, has fine-tuned her epistemic logic through considered deliberation, during a 35 year academic career, of the issues raised by euthanasia in light of accepted first principles. The former has acquired knowledge through "reflection in action", the latter out of purposeful "reflection on action".

A dual conception of reflective thought has recently been expanded to include two additional elements. Occupational

therapist and education theorist Anne Kinsella<sup>43</sup> has argued that there is a "pre-reflective and receptive" stance in which one human, unconstrained by the means of language, recognizes another human affectively and precognitively, and, as well, a stance of "reflexivity". Reflexivity involves "the act of interrogating interpretive systems"; it assumes that meaning-making is a collective endeavor influenced by historical conditions and contexts. This is more far-reaching than the internal and individual contemplation usually equated with reflective thought. In a spirit of reflexivity, we have considered and analyzed the phenomenon of euthanasia.

Our analyses and investigations of both practical and theoretical issues raised by euthanasia, have culminated in a profound belief that euthanasia is harmful to individuals, especially vulnerable people, physicians, the institutions of law and medicine, and society, and that the healing role of physicians and euthanasia are simply not miscible; indeed, they are antithetical.

#### Further information

Readers who require more detailed information concerning the reference list and cited texts should contact the corresponding author by email.

## **Disclosure**

The authors report no conflict of interest in this work.

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## **Euthanasia is not medical treatment**

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**Introduction or background**: The public assumes that if euthanasia and assisted suicide were to be legalized they would be carried out by physicians.

**Sources of data**: In furthering critical analysis, we supplement the discourse in the ethics and palliative care literature with that from medical education and evolving jurisprudence.

**Areas of agreement**: Both proponents and opponents agree that the values of respect for human life and for individuals' autonomy are relevant to the debate.

Areas of controversy: Advocates of euthanasia and assisted suicide give priority to the right to personal autonomy and avoid discussions of harmful impacts of these practices on medicine, law and society. Opponents give priority to respect for life and identify such harmful effects. These both require euthanasia to remain legally prohibited.

**Growing points**: Proposals are emerging that if society legalizes euthanasia it should not be mandated to physicians.

Areas timely for developing research: The impact of characterizing euthanasia as 'medical treatment' on physicians' professional identity and on the institutions of medicine and law should be examined in jurisdictions where assisted suicide and euthanasia have been de-criminalized.

*Keywords:* euthanasia/assisted suicide/palliative care/suffering/healing/medical legislation

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....tha'll nivver feel it, tha'll be out of existence i' two minutes

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## **Background**

Physician-assisted suicide (PAS) and euthanasia are among the most contentious issues faced by the medical profession. Numerous scholars have argued in favor of or against 'assisted death', as these interventions are euphemistically called. These debates generally take it for granted that the person carrying out euthanasia will be a physician. That assumption has been questioned, most recently, by two ethicists from the Harvard Medical School who propose a limited role for physicians in assisted dying. We discuss their proposal shortly. The possibility of deleting the physician from the equation has certainly not been salient in professional discourse.

In this article we will examine factors, highlighting historical contexts and the influence of language, which have helped campaigners who aim to sanitize 'assisted dying' by associating it with medicine. We broach the issue of whether euthanasia can be considered medical treatment by focusing on the irreconcilability of euthanasia with medicine's mandate to heal.

In the remainder of this text, we use the word euthanasia to include PAS, unless the contrary is indicated. We do so in accordance with the fact that both procedures raise the same ethical and legal considerations with respect to many of the issues discussed in this article. In PAS and euthanasia, physicians and society are complicit in helping persons to commit suicide or giving them a lethal injection, respectively. Moreover, whether or not a society will alter its laws to allow 'medically induced death' is a binary decision.

## The implication of a medicalized dying process

Are medical doctors, by being responsible for the prolongation of the dying process, blameworthy for the existence of conditions that elicit a desire for hastened death? The profession has indeed created circumstances, through overly aggressive technical interventions, whereby persons' illness narratives have included chapters with alienating, depersonalizing and dehumanizing plots and characters. The following trajectory of a hypothetical patient with amyotrophic lateral sclerosis is all too common: first, non-invasive nocturnal ventilation enters the scenario; next, a wheelchair; then a Dobhof feeding tube, promptly replaced by a jejunostomy; innumerable venous punctures and catheterizations; intervening urinary tract infections; recurrent aspiration pneumonias, followed by invasive ventilation, eventually necessitating a tracheostomy; accompanied by unremitting despondency; and finally,

progressive somnolence and terminal sepsis. Too many patients find themselves in a sickroom in such a state, one of spent physical resources and suspended hope or even total despair. Some would add that this metaphoric dwelling is also inhabited by a crushed spirituality.

Pro-euthanasia advocates sometimes present such scenarios to support their views that the profession is, in some measure, responsible for the condition in which a patient may conceive of no escape or redress other than self-willed death. A comment such as, 'I'd rather die than slog on with deformity, disfigurement and disability', is not infrequently heard and, when expressed, often denounces a sequence of medical interventions rather than the original illness. In dire situations, one of the few avenues that can seem to offer a sense of comfort is that of personal control. Control, usually packaged in a discursive frame of politico-judicial personal autonomy, can be manifest as a desire to manage the ultimate mode of exit from life, that is, for patients to select the method, place and hour of their death. Moreover, some may want this stance to be legitimized by societal approval and even see it as a heroic act and as furthering a common cause, by promoting shared values and ideologies.<sup>4</sup>

It would, however, be an overstatement to attribute all changes in the nature of death to the health professions. Improvements in general socioeconomic conditions have decreased the incidence of death from catastrophic accidents, trauma and obstetrical mishaps and have lessened the impact of previously deadly infectious diseases. Undeniably, the shift in prevalence from acute and preventable conditions to chronic degenerative diseases, as well as many cancers, is a consequence of a prolongation of life resulting from improvements in public health, universal literacy and preventive interventions. Nonetheless, there is a kernel of truth in the notion, expressed in commentaries dating from Hellenistic to modern times, that physicians have invented 'lingering' death.<sup>5</sup> We believe that some of the profession's approaches in responding to illness in modern society may have fueled the clamour for radical solutions such as euthanasia.

The process has been abetted by those who espouse so-called 'progressive values', in what are often referred to as the 'culture wars', and who often manifest a pervasive questioning of authority. A desire for unfettered individual decision-making powers—seeing 'radical autonomy' as always being the overriding value—and the demotion of established religions as influential voices in the public square are also important factors in the rise in demands to legalize euthanasia. We consider euthanasia a misguided solution to a complex socio-cultural transformation. It is reasonable that the medical profession not deny its contributions to the situation; but, it would be perverse if it allows

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itself to be co-opted by a perceived need for atonement. It must be vigilant to avoid over-compensating by endorsing society-sanctioned euthanasia.

The profession must not disown its ethical tradition or abandon its basic precepts. The potential harm is not only to individuals, but also to the institutions of medicine and law and the roles they play in society, especially in secular societies, where they are the primary carriers of the value of respect for human life, at the level of both the individual person and society. Ironically, they are more important in this regard now than when religion was the main carrier of the value of respect for life. Therefore, the degrees of freedom, in terms of legitimate actions and behaviours available to physicians confronted with a dying patient are, and must remain, clearly and strictly limited.

## The historical case against physicians assisting suicide

The injunction against physician involvement in hastening death has recurred throughout recorded history, the Hippocratic Oath providing the following emblematic statement: 'I will neither give a deadly drug to anybody if asked for it, nor will I make a suggestion to this effect'. This unambiguous prohibition has oriented medical practice towards specific ends and means and away from certain others for over 2400 years. Its enduring impact was apparent in early-modern Western society. Euthanasia was discussed by the lawyer Casper Questel in a book entitled 'De pulvinari morientibus non subtrahendo'. Translated as 'On the pillow of which the dying should not be deprived', it described common practices that were thought to hasten death. These popular practices included removing pillows from dying persons so that, with their bodies completely supine, ventilatory capacity would be constricted and death accelerated. Another strategy was to transfer dying persons from their beds to the ground. Perhaps the latter operated through a tacit understanding that the bodily cold thereby induced would bring dying persons closer to their natural demise. Regardless of the underlying pathophysiologic mechanism, it is highly probable that symbolism (for example, facilitating passage of the soul from the shell of the dying body to life eternal) was at play. We note that it was natural death that was sought, not terminating the life of the person.

An intriguing and noteworthy feature of this ancient text is that such practices were popular amongst the general public. They were not acts delegated by society to a particular group and certainly not restricted to medical doctors. Questel was aware of undesirable ramifications if they were practiced by physicians. Physicians risked losing trust should they be discovered to have intentionally shortened the lives of dying

patients. Trust is of paramount importance to a successful doctorpatient encounter and is indispensable to the implicit moral contract between the profession and society. Maintaining the trust of individual patients and of society is a sine qua non for the maintenance of professional status. Participating in euthanasia carries the risk of vitiating trustworthiness.

Constraints on physician complicity in euthanasia are to be found throughout history. An 1826 Latin manuscript by a physician, Carl Friedrich Marx, referred to medical euthanasia as the skillful alleviation of suffering. 10 He absolutely forbade physicians from engaging in any attempt at accelerating death, stating: '... and least of all should he be permitted, prompted either by other people's request or his own sense of mercy, to end the patient's pitiful condition by purposefully and deliberately hastening death'. Examples of more recent statements of such prohibitions include the defeat in the House of Lords in 1932 of the 'Voluntary Euthanasia Bill' and the Canadian parliament's clear rejection in 2010, by a vote of 228 to 59, of Bill C-384, a private member's bill that would have permitted PAS and euthanasia. 12

Certain jurisdictions, notably the Netherlands and Belgium, have legalized euthanasia. In America, Oregon's 'Death with Dignity Act', which permits PAS, came into force in 1997 and Washington state followed suit in 2008. However, on 6 November 2012, Massachusetts voters defeated a ballot that would have allowed assisted suicide, 51-49%. There have been discussions, debates and proposed legislation in many other American states and other countries in the recent past. Generally, these have reaffirmed the ban on medical assistance in killing (whether in the context of end-of-life or, in the USA, physicians' involvement in carrying out capital punishment through lethal injections). The Benelux and a few American states represent the exception to the rule. 'Do not kill' has been considered a moral absolute for most physicians for millennia, and remains so for physicians even in jurisdictions where the public has looked favorably on legislative change. That medicine has all to do with healing, and nothing to do with the purposeful ending of life, has been a reverberating imperative throughout history.

## The medical cloak

The pro-euthanasia lobby derives advantages by aligning itself tightly with medicine and physicians. The history of physician involvement in capital punishment is illustrative of this strategy. Juries in the USA, who had seen horrific footage of convicted murderers being executed in the 'electric chair', became reluctant to convict persons accused of

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capital offences or to vote for a death sentence for felons convicted of a capital offence. Most physicians and the American Medical Association adamantly opposed medicine's involvement in administering capital punishment by lethal injections. Nevertheless, some physicians participated. By virtue of their involvement and in concocting a method of execution that makes a convicted criminal appear serene during final moments, enhanced acceptability was conferred on the procedure. It has been suggested that 'the law turned to medicine to rescue the death penalty'.<sup>13</sup>

It is germane to point out that the word 'doctor' is linked etymologically to 'teacher'. The Oxford English dictionary's definition is: 'one who gives instruction in some branch of knowledge, or inculcates opinions or principles'. <sup>14</sup> Medical doctors can influence public opinion, much as teachers contribute to the socialization of their pupils. The recruitment of doctors, both as a collectivity and as individuals, to undertake a procedure, can greatly modify the public's view of that procedure.

Language is critically important in not only reflecting, but also creating reality. For example, the field testing conducted prior to the passage of the Oregon Death with Dignity Act demonstrated that when the intervention was described as 'suicide' or 'euthanasia', popular support declined by 10-12%. The phrase 'death with dignity', by avoiding the negative connotations of suicide, was perceived as less alarming. It was able to create a halo of benignity and to generate greater support for and muted opposition to the proposed law. For similar reasons, the euphemism 'physician assistance in a dignified death' is reassuring. It would be rare indeed for an individual to wish explicitly for a gruesome death or want to banish a benevolent healer from the sickroom. Research shows that emotions, 16 which we would qualify as 'examined emotions', and we would add, moral intuition, are important in making good ethical decisions. Choice of language affects both these human ways of knowing what is morally right and morally wrong. 17

Jill Dierterle, a member of the Department of History and Philosophy at Eastern Michigan University, denigrates the validity and power of words in order to claim that none of the anti-PAS arguments hold merit and concludes that 'we have no reason not to legalize it'.<sup>18</sup> She turns a blind eye to any potential harm and conveniently overlooks the lacuna in current data-gathering procedures or impact assessments. This stance flies in the face of the golden rule of medicine: primum non nocere. Hence, it is anathema to the vast majority of practicing physicians. Few of us, presented with a new and relatively untested therapeutic instrument, would conclude, 'we have no reason to doubt its safety; let's forge ahead'. Her nonchalant dismissal borders on the offensive. Note how

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she handles an important deontological argument against PAS: '...if PAS is wrong, its wrongness cannot be constituted by its conflict with the Hippocratic Oath. After all, the Hippocratic Oath itself is just a bunch of words'. With the phrase 'just a bunch of words' Diertele implies that the oath is hollow and meaningless. But ethical precepts and laws are also just a 'bunch of words', yet they establish our metaphysical reality—what can be called our metaphysical ecosystem—which, depending on its nature, determines whether or not we have a society in which reasonable people would want to live.

It is critical to the euthanasia debate to consider what role, if any, physicians may, should or must not play. It is not a 'given' that, were euthanasia to be legalized, it would be inextricable from the medical mandate. We propose that it is in the best interests of individuals and society to remove the medical cloak from euthanasia in order to lay bare fundamental arguments against it. The stakes are too high to have the veneer of doctoring obscure the essential core of what is involved and its potential harms and risks.

## **Collaborators in euthanasia**

The commentary previously mentioned, 'Redefining Physicians' Role in Assisted Dying', suggests that a non-physician group could be made responsible for the 'active' role in euthanasia.<sup>3</sup> The label 'thanatologist' has been suggested for such a group.<sup>11</sup> The possibility that a new discipline might emerge raises a set of intriguing questions: What would be the scope of practice of thanatologists? Where would one draw the line between 'active' and 'passive' roles? Of what might their education consist? We want to make it clear that we believe euthanasia is inherently wrong and, therefore, should never be undertaken, but, it is important to consider what such a proposal could involve if it were put into practice.

It is reasonable to speculate that the training could be offered in a program at a technical level and that the duration of training period would be modest. The act of terminating someone's life is thought to be fairly straightforward—at least, the execution of it is not overly complicated. The experience in the UK of recruiting and training hangmen can provide useful clues. Executioners were trained in the late 19th to mid-20th century with a 5-day course that included lectures, a practical component—'applicants to pass pinioning in the presence of the Governor'—and ended with a written examination that included simple algebra—the applicant was required to calculate the length of drop (i.e. stretch of the rope) for men of varying weights. Given the complexity of drug-based protocols used in euthanasia,

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5 days of instruction would likely be insufficient. A program in the order of 24 weeks, as is the case for cadet training in many police academies, might allow for core objectives to be adequately covered and relevant abilities to be tested and credentialed.

A provocative essay on the topic suggests that lawyers could be trained in euthanasia, practicing a new specialty called legistrothanatry.<sup>20</sup> Although admittedly implausible, the proposal serves to foreground pragmatic issues relevant to the debate. It rests on two fundamental assumptions: (i) that lawyers are trained to interpret laws and regulations accurately, to apply them strictly and to act on the basis of implementing patients' values and (ii) that carrying out the required tasks does not require sophisticated technical expertise. The authors state, 'Attorneys who wish to provide this service would require only a small amount of additional training'. <sup>20</sup> An appropriate educational blueprint could include the following cognitive base: the physiology of dying, basic pharmacology and an overview of the historical, ethical and legal aspects of natural and requested/assisted death. The toolkit of required skills would likely include: communication, verification of decision-making capacity and informed consent, securing of intravenous access, supplying and/or administering of lethal drugs, management of complications, accurate recognition of death and completion of death certificates. The desired attitudinal substrate would include: personal resolve (that is, stick-with-it-ness), respect for individuals' rights to autonomy and self-determination, and, ideally, a calm demeanour.

Although the tone of the previous discussion may be—and should be—rather 'chilling', the substance it addresses has clearly gained a foothold in the current medical literature. A description of procedures for successful euthanasia has been published; one is entitled 'Euthanasia: medications and medical procedures'. 21 It includes protocols for dealing with terminal dyspnea or agitation in the terminal phase, euthanasia, and the induction of 'controlled sedation'. Controlled sedation is placed in inverted commas by the author, presumably because he feels that it needs qualification; in his opinion, it represent a hypocritical response to suffering and is undertaken with the aim of muzzling the patient while he dies. We note, but will not discuss here, the ethical issues raised by 'palliative sedation', sometimes called 'terminal sedation', in which the dying patient is sedated in order to relieve otherwise unrelievable suffering. We suggest that the former term should be used when sedation is the only reasonable, medically indicated, way to relieve the patient's suffering (when it is not euthanasia); the latter term is appropriate when those conditions are not fulfilled and the doctor's intention is to hasten the patient's death (when it is euthanasia).

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The epigram to the euthanasia guidelines cited above is fascinating. It states: 'One summer evening, Mr J-M L, suffering from Charcot's Disease, passed away peacefully after having asked for and obtained the assistance of a physician. Upon leaving the home, the latter did not ponder: 'What did I do?' but rather, 'Did I do it well?' (Translation by author [DB]<sup>21</sup> This formulation reveals a unique mindset. The affective and moral stance expressed in that quote is closely aligned to a technical perspective, one where the emphasis is on accomplishing tasks with self-efficacy as opposed to one embellished with critical reflection. Meta-reflection is an important aspect of doctoring. What we do and the conversations we routinely engage in forge who we become; they become a habitus. Even the clothing we wear can influence our thought processes. For example, a recent article documents the impacts on cognition of donning a lab coat.<sup>22</sup> If the simple habitual act of wearing a white lab coat can affect thinking and action, one can easily imagine the harmful impacts of regular discussions of euthanasia as they insinuate themselves into the ethos of medical care.

'The Executioner's Bible', a story of England's executioners in the 20th century, describes the work of the hangman as a 'cold, clinical operation'. 19 The epigram we have chosen for our essay, extracted from that textbook, is a quote from James Billington, the UK's Chief Executioner from 1891 to 1901. It is intended to evoke calculated efficiency. The author of 'Euthanasia: medications and medical procedures' is similarly categorical, prescriptive and unrestrained by self-doubt. For example, he advises the physician not to propose suicide without medical assistance; to do so is considered incompatible with the role of the physician. He warns the physician against using 'violent options' (such as injecting potassium chloride) as this is considered contrary to medical ethics. Leaving aside a disregard for the value of respect for life, the punctilious euthanizer can be seen as behaving with professional dignity and serenity, within a priori defined limits. As the Home Office stated in 1926, when describing the work of hangman William Willis, '....even an executioner can remain humane and decorous'. 19 Our purpose in making this historical link is not to denigrate advocates of euthanasia. Rather, through this analogy we are endeavoring to focus on the act itself and not just the actor. The latter is often well meaning.

Thanatologists, given the narrow focus of their field of expertise would, over time, almost certainly develop clinical practice guidelines; these might be tailored to different illness categories, for instance, neuro-degenerative diseases and the various cancers with poor prognosis. This process seems to be well underway. For example, a recent paper explores euthanasia requests and practices in a highly particularized context, namely, patients in Belgium dying of lung cancer.<sup>23</sup> If euthanasia is

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accepted as integral to 'medical care', this sort of disease-specific focus will surely expand. One can envisage the emergence of guidelines delineating the complementary roles of physicians and thanatologists. Most physicians (we hope) would eschew any involvement in euthanasia and confine themselves to traditional roles such as diagnosing, estimating prognosis and providing supportive care and symptom control, that is, excellent palliative care—which does not include euthanasia, as some advocates argue it should.

The extent to which principled opponents of euthanasia would be legally 'excused' from participating in the steps leading up to fulfilling a patient's request for assisted death is a contentious aspect of the debate. How would the profession balance the requirement for individual physicians to fulfill specific social roles and the need to respect the freedom of conscience of those who, on moral grounds, reject certain options? Physician-philosopher Edmund Pellegrino argues that physicians can refrain from entering into professional relationships that have the potential to erode their moral integrity; he offers strategies to assist the physician in navigating potential conflicts.<sup>24</sup>

Psychiatrists and medical ethicists who do not reject euthanasia would be expected to focus on soliciting patient perspectives, exploring options and assessing comprehension, competence and voluntariness that in making her decision, the patient is free from coercion, duress or undue influence, assuming this is possible. The profession has begun to equip itself with tools to deal with this incipient new clinical reality in jurisdictions which allow euthanasia. Physicians in the USA have been provided with an eight-step algorithm to assist them in discussing assisted suicide with patients who request it.<sup>25</sup> These guidelines were developed immediately after the legalization of PAS in Oregon. It is reasonable to expect that additional decision-making tools will emerge should the practice gain wider societal acceptance. Also, the possible consequences on undergraduate medical education, should it have to include protocols for ending patients' lives, have been explored.<sup>26</sup>

Again, we note that the above discussion is included for the sake of comprehensive coverage of the issue of physicians' involvement in euthanasia, were it to be legalized, and whether it could be ethically acceptable 'medical treatment' or even 'therapy'. It is not meant to signal that we see euthanasia as ethically acceptable.

## **Healing and euthanasia**

It has been repeatedly found that of all separately identified groups in Western societies, physicians are among the most opposed to involvement in euthanasia. There is substantial indirect evidence to support

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this claim, even in jurisdictions in which doctor-assisted death is legal. For example, in Oregon, there is a suggestion that some patients have to resort to 'doctor shopping' to obtain their lethal medications. The Oregon Public Health Division's annual report for 2011 shows that one physician was responsible for 14 of the requisite prescriptions out of a total of 114 that year.<sup>27</sup> Also, the Netherlands recently approved the launching of mobile euthanasia clinics. A stated reason for this development was that patients' goals in self-determination were being thwarted by physician resistance to providing euthanasia. Not all physicians, including many Dutch colleagues, are on-side with having euthanasia become a medical act.

A questionnaire-based study comparing the opinions of the Dutch general public with that of physicians revealed some marked differences. With respect to the active ending of life for patients with dementia, the level of acceptance was 63% for the public and 6% for physicians.<sup>28</sup> With respect to terminally ill cancer patients, the figures were much higher and less divergent; this may be a consequence of the prolonged experience of euthanasia in cases of terminal illness in the Netherlands. Or, it might be that often survey questions are phrased as, 'If a person is in terrible pain, should they be given access to euthanasia?' The respondent must choose between leaving the person in pain and euthanizing them. But this choice is wrongly constructed. The person should be able to choose fully adequate pain management that is, the 'death' of the pain—without having to endorse the intentional infliction of death on the patient.<sup>29</sup> Despite high levels of acceptance by physicians of euthanasia for cancer patients in the Netherlands, recent reports reveal persistent ethical concerns.<sup>30</sup> It is also noteworthy that physicians involved in palliative care, including in Britain, appear to be particularly concerned about legalizing euthanasia.<sup>31</sup>

What underlies the medical profession's reluctance to accept euthan-asia? There are multiple explanations. Aside from ethical, moral and religious beliefs, one of the most salient and compelling has to do with one's conception of the medical mandate, especially as it relates to healing. Healing is a challenging term to define. Many in our institution (the Faculty of Medicine, McGill University) consider it to be 'a relational process involving movement towards an experience of integrity and wholeness'. It has been operationally defined as 'the personal experience of the transcendence of suffering'. A feature of healing important to our thesis is the notion that healing does not require biological integrity. Although it may seem counter intuitive at first glance, it has been pointed out that if a sick person is able to construct new meaning and is able to achieve a greater sense of wholeness, that individual may 'die healed'. It is undeniably a vastly different concept

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than curing, although they are not in opposition one to the other. Most physicians accept the healer role as a fundamental and enduring characteristic of the profession.<sup>34</sup> In our undergraduate medical program, this concept is taught using the term 'physicianship'; it refers to the dual and complementary roles of the physician—the physician as healer and professional.<sup>35</sup> It could be argued that one can remain 'professional' even while serving as a collaborator in requested death. On the contrary, many commentators—the American Medical Association is a prime example<sup>36</sup>—believe that it is impossible to do so as a 'healer', one who is focused on accompanying the patient on a transformational journey towards personal integrity that transcends the embodied self.

The process of healing in the doctor-patient relationship is poorly understood. We do not have a complete picture of how it is initiated or which clinical skills or abilities are essential in fostering a healing relationship. The literature suggests that healing resides in the quality of interpersonal connections and that it requires a deep respect for the agency of the physician in the therapeutic process.<sup>37</sup> An appreciation of the placebo effect, or in more poetic terms, the 'doctor as the medicine', is required.<sup>38,39</sup> It is almost certainly linked to the phenomena of transference and counter-transference and it may utilize the power differential for salutary purposes, even if these phenomena operate largely at a covert level.

The patient-doctor relationship is marked by intense ambivalence. Any physician who has initiated a discussion with a patient on the issue of resuscitation or desired level of technical intervention will realize how easily it can be misinterpreted, how quickly it can catalyze existential angst and how thoroughly it can overwhelm hopeful sentiments. Affective turmoil and cognitive dissonance can rapidly ensue. These sorts of cross-purpose exchanges would surely be magnified in the context of discussions regarding euthanasia. Although there may be a productive 'meeting of the minds' in any specific doctor-patient dyad, the risks of emotional derailment, self-effacing dependency and irremediable miscommunication should not be minimized. It is inconceivable to us that deep layers of existential suffering would not be activated and exposed by such a discussion. A healing space that can support patients would be unnecessarily deflated. Admittedly, this belief is based on incomplete understandings of the clinical encounter, yet the axiomatic foundation of that encounter is anchored in a 2400-year old tradition. We must consider why we have so jealously guarded that tradition. We could always have abandoned it by accepting euthanasia. Unlike many other current medical-ethical dilemmas, neither death nor euthanasia is a novel issue presented by new technoscience.

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#### **Recent developments**

Many proponents of euthanasia like to claim that opponents rely on two types of unsound arguments: one based on empirical data and the other anchored in axiology. In the first instance, they allege that the outcomes data available from jurisdictions where euthanasia or assisted suicide has been legalized, suggest that our fears of potential abuse are groundless. They deny that there is a 'logical' slippery slope—that the situations in which euthanasia will be available will expand over time—or a 'practical' slippery slope—that euthanasia will be used abusively. Pro-euthanasia advocates claim that evolving legislation does not pose a threat to persons with a disability, does not lead to euthanasia without consent, does not invite extension of the practice to vulnerable populations—in short, that it has not become a 'run-away train'. They usually express satisfaction with individual clinicians' professional restraint and integrity as well as with administrative safe guards. Some suggest that the acceptance of euthanasia results in improvements in traditional palliative care. This belief that it represents a positive force for changing prevailing clinical practices is not based on robust evidence. Moreover, the evidence for the existence of a practical slippery slope is very convincing. This was very recently affirmed by the High Court of Ireland, in a judgment we discuss shortly, in deciding whether prohibiting assisted suicide contravened the Irish Constitution, which it held it did not.<sup>40</sup>

A recent dramatic example of the logical slope's gravitational pull is the euthanizing, in December 2012, of 45-year-old twins in Belgium. Deaf since childhood, Marc and Eddy Verbessem were facing the additional disability of blindness. Accepting that they were irremediably suffering, their physician euthanized them. Euthanizing patients with non-terminal conditions, even though it can be legal in Belgium, will surely meet with the disapproval of most physicians. Even within the pro-euthanasia movement, this development may be considered an aberration. Nonetheless, there are increasing numbers of commentators who subscribe to the following philosophy: 'If a patient is mentally competent and wants to die, his body itself constitutes unwarranted life-support unfairly prolonging his or her mental life'.

There are two arguments, both warranting careful scrutiny, frequently advanced in support of physician involvement in euthanasia. The first is that physicians have privileged access to information about their patients' unique perspectives and circumstances, including personal resources and frailties, as well as complex family dynamics. That argument has been undermined by evolving practices. The 'Oregon Public Health Divisions' report for 2011 reveals that the median length of the

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doctor-patient relationship for those who died by PAS was merely 12 weeks (with a range of 1–1379 weeks).<sup>27</sup> It is highly unlikely that a physician would have acquired a sophisticated understanding of a person's values, hopes and fears in the matter of a few weeks. It is even less plausible in the case of the mobile euthanasia units currently being deployed in the Netherlands. The second argument is that physicians are inclined, by temperament and experience, to accompany their patients throughout the illness trajectory, including death. That too is not defensible on the known facts. For example, in Oregon, in the first 3 years of the administration of Oregon's 'Death with Dignity Act', physicians were present at approximately half of assisted deaths. By 2005, it was 23%. In 2011, it was a mere 9%.<sup>27</sup> The behaviour of these prescribing physicians is not congruent with the image of physicians represented in that iconic painting by Sir Luke Fildes, bearing the title 'The Doctor', and often used to portray empathic witnessing. Pro-euthanasia advocates can come across as rather intrepid in their defense of personal autonomy. Autonomy is the overriding principle that is used to buttress arguments in favor of euthanasia; indeed, it generally runs roughshod over all other considerations. Many pro-euthanasia commentators are disposed to brush off concerns about the impact of accepting 'radical autonomy' as always being the overriding value—especially concerns about the risks and harms to vulnerable people and to important shared values, in particular, respect for life at the societal level. A 2012 case in British Columbia manifests all these issues; it involved vulnerable persons, values conflicts and shows the preferencing by the court of the value of individual autonomy in relation to euthanasia. The case originates in a challenge to the Canadian Criminal Code's current prohibition of assisted suicide.43

Gloria Taylor, a plaintiff in the case, Carter v Canada (Attorney General)<sup>44</sup>, was a person with ALS who requested assisted suicide arguing that as her illness progressed she would be incapable of committing suicide, unaided, due to her physical disability. The judge, Justice Lynn Smith, ruled in the plaintiff's favour on the basis that the prohibition was unconstitutional on the grounds that it contravened both Ms Taylor's constitutional 'right to life, liberty and security of the person' (under section 7 of the Canadian Charter of Rights and Freedoms)<sup>45</sup> and her right not to be discriminated against as a physically disabled person (under section 15 of the Charter); and that the prohibition could not be saved (under section 1 of the Charter), as a reasonable limit on constitutionally protected rights. Consequently, the judge held that the law prohibiting assistance in suicide was not applicable with respect to preventing Ms Taylor and other people in similar circumstances from having such assistance. The judgment is very long

and legally complex and is now on appeal. Read as a whole, it strongly supports legalizing PAS and euthanasia.

Criticisms of the judgment include that it gives undue weight to the evidence of expert witnesses who favour legalizing euthanasia, while overly devaluing that of those who oppose it. The High Court of Ireland, in a case with similar facts to the *Carter* case, in that the plaintiff had an advanced debilitating neurological disease and, likewise, was seeking to have the prohibition on assisted suicide struck down, summed up this aspect of the *Carter* case as follows:

In that case, the Canadian court reviewed the available evidence from other jurisdictions with liberalised legislation and concluded that there was no evidence of abuse. This Court also reviewed the same evidence and has drawn exactly the opposite conclusions. The medical literature documents specific examples of abuse which, even if exceptional, are nonetheless deeply disturbing. Moreover, contrary to the views of the Canadian court, there is evidence from this literature that certain groups (such as disabled neonates and disabled or demented elderly persons) are vulnerable to abuse. Above all, the fact that the number of LAWER ('life-ending acts without explicit request') cases remains strikingly high in jurisdictions which have liberalised their law on assisted suicide (Switzerland, Netherlands and Belgium) – ranging from 0.4% to over 1% of all deaths in these jurisdictions according to the latest figures – without any obvious official response speaks for itself as to the risks involved'.<sup>40</sup>

One can also question Justice Smith's conclusions that PAS is not inherently unethical; that individuals' right to autonomy takes priority over the value of respect for life; that sanctity of life is only a religious value; that there is no relevant ethical or moral difference between refusals of life-support treatment that result in the death of the patient and euthanasia; and, that the availability of legalized PAS is necessary 'medical treatment' for some.

#### Is euthanasia medical treatment?

Justice Smith's justification for allowing euthanasia is largely based on a selective application of *Canadian Charter of Rights and Freedoms* jurisprudence<sup>45</sup> and depends upon her being able to distinguish the binding precedent set by the Supreme Court of Canada in the *Rodriguez* case.<sup>46</sup> The latter held, in a four to three split among the judges, that the Canadian *Criminal Code's* prohibition on assisted suicide<sup>43</sup> was constitutionally valid.

Invoking the Canadian Charter of Rights and Freedoms, Justice Smith ruled that Ms Taylor's right to life was infringed by the

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prohibition of assisted suicide because she might conclude that 'she needs to take her own life while physically able to do so, at an earlier date than she would find necessary if she could be assisted'.<sup>44</sup> We believe that this would strike many as a straw man argument. It is to convert a right to life to a right to assisted suicide, by accepting as a breach of a right to life that a person will commit suicide sooner, if not given access to assisted suicide. But validating assistance in committing suicide hardly upholds a right to life.

Like everybody else, Ms Taylor has a right to refuse treatment even if that means she will die sooner than she otherwise would. Justice Smith accepts the plaintiffs' argument that there is no ethical or moral difference between euthanasia and refusals of life-support treatment that result in death and, therefore, both should be legal. But a right to refuse treatment is based in a right to inviolability—a right not to be touched, including by treatment, without one's informed consent. It is not a right to die or a right to be killed. At most, people have a negative content right to be allowed to die, not any right to positive assistance to achieve that outcome. A person with Ms Taylor's illness trajectory will surely die—even more precipitously if they decline many of the interventions described in the hypothetical patient with ALS we introduced earlier on. (Subsequent to the judgment, Ms Taylor died a natural death from an infection). It is also important to underline that current medical practices enable physicians to attenuate much of the suffering that may accompany the progressive loss of function and wellbeing in advanced ALS.

The judge appears also to accept the argument that legalizing euthanasia enhances palliative care. This goes some way towards treating euthanasia, as some have termed it, 'the last act of good palliative care'. <sup>47</sup> It is also consistent with the 'no-difference-between-them approach' to a spectrum of end-of-life medical interventions. Euthanasia is confused with interventions, such as pain management and rights to refuse treatment, which are ethically and legally acceptable, and an argument is thus set up that, if we are to act consistently, euthanasia must also be ethically and legally acceptable. It is tantamount to legalizing euthanasia through confusion. <sup>48</sup>

Justice Smith turns to the British Columbia Prosecutorial policy on assisted suicide for definitional assistance with respect to whether PAS is medical treatment. Here's what she says:

In the policy, 'palliative care' is defined as 'a qualified medical practitioner, or a person acting under the general supervision of a qualified medical practitioner, administering medication or other treatment to a terminally ill patient with the intention of relieving pain or suffering, even though this may hasten death'. The policy states that that conduct,

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'when provided or administered according to accepted ethical medical standards, is not subject to criminal prosecution'. 44

In other words, the policy's definition of palliative care can be expansively interpreted to place euthanasia in same category as other end-of-life interventions which may hasten death.

For the sake of exploration of the issue, let us assume momentarily that euthanasia is medical treatment. What might flow from this?

Classifying euthanasia as medical treatment would affect the scope of disclosure of information necessary to obtain informed consent. A physician must disclose to the patient all reasonably indicated medical treatments as well as their risks and benefits. It would now have to include euthanasia. Even most pro-euthanasia advocates regard it as unethical for a physician to introduce the possibility of euthanasia. Currently, it is generally accepted that any discussion of it must be initiated by the patient.

It would also mean that to obtain informed consent to euthanasia, all reasonably indicated treatments would need to be offered and they would certainly include all necessary palliative care, in particular, fully adequate pain management. Many of those advocating for euthanasia posit euthanasia and palliative care as alternatives, but informed consent to euthanasia could not be obtained unless good palliative care was available. This is not available to a majority of people who die in Canada; it has been estimated that less than 30% have access to even the most minimal form of palliative care.

As well, Canadian psychiatrist Dr Harvey Max Chochinov, who specializes in psychiatric treatment for dying people, has shown that there are significant fluctuations in the will to live, even as death is imminent. The impact of these findings, as well as conditions such as depression, on the possibility of obtaining valid informed consent to euthanasia would need to be fully addressed.

Another crucially important issue is that, if PAS and euthanasia are 'medical treatment', then surrogate decision-makers have the authority to consent to them for the patient. Their decisions must be based on either their knowledge of what the patient would have wanted or, if those wishes are unknown, their belief that these interventions are in the 'best interests' of the patient. Would mentally incompetent people and those with dementia or disabled newborn babies, as is now the case in the Netherlands under the Groningen protocol, be eligible for 'therapeutic homicide'?<sup>51</sup>

Yet another issue is what would be the indications for euthanasia as medical treatment and who could access it if were legalized? Justice Smith, citing an expert witness for the plaintiffs, refers to 'the end-of-life population'. This is a term used in the Royal Society of

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Canada Expert Panel Report on *End of Life Decision-Making*. <sup>52</sup> In the report, this population is defined as those persons on a continuum beginning with any serious diagnosis or injury. This represents an expansion of a term, 'end-of-life', traditionally used for those inevitably in the last days of life, to all people with serious chronic conditions, resulting from illness or injury, that may be fatal in the course of time. And, of course, it is notoriously difficult to predict with any certainty the timing of even obviously terminal illnesses. It is precisely the type of 'slippery slope' that we fear emerging from the 'limited' exception, as defined by Justice Smith. It will likely culminate in more decisions similar to that taken in the case of the Verbessem brothers in Belgium.

It is also pertinent to point out that Canada continues to fund and promote programs that aim to prevent suicide. If suicide is conferred the status of a right or is held to be acceptable medical treatment it would be difficult to reconcile this situation with the presence of programs that aim to actively thwart it. Some resolve this dilemma by trying to banish the word 'suicide' from the debate, in favor of the phrase 'assisted dying'. Marcia Angell, erstwhile editor of the NEIM and a fervent proponent of PAS, endorses the notion that 'assisted dying' can be distinguished from 'typical suicide'. The latter is described as being undertaken by someone with a normal life expectancy, whereas the former is carried out in someone 'who is near death from natural causes anyway'. 53 They are going to die anyway, so what does it matter?! We believe that this reasoning is rather disingenuous and that it can result in a dishonouring of that segment remaining in someone's life, whether this is measured in minutes or months, and could deprive them of something as ephemeral as dreams and hopes. It certainly negates the idea of dying as our last great act of living.<sup>54</sup>

Finally, a decision classifying euthanasia as medical treatment could have impact far outside the context of issues directly related to death and dying. For example, in Canada, the federal and provincial governments' respective powers are allocated under the Canadian Constitution. The criminal law power belongs to the federal parliament and the power to govern health and social services to the provincial legislatures. If euthanasia was defined as medical treatment, the federal parliament's prohibition of it in the Criminal Code could be invalid by reason of its trespassing on the provincial jurisdiction to govern health and social services. That is one reason that the Quebec College of Physicians and Surgeons, which supports legalizing euthanasia, argues that it is medical treatment. Likewise, the Quebec Legislative Assembly committee, which issued a report, 'Dying with Dignity', 55 adopts the same argument. From past experience, we expect that Quebec might challenge the constitutional validity of the Criminal Code prohibition on this basis. However, a legal committee, set up by the Quebec government, has proposed another approach. It has just reported on how Quebec could operationalize giving doctors legal immunity for carrying out euthanasia, including by the Attorney General of Quebec instructing Crown Prosecutors not to prosecute them under the *Criminal Code* for doing so, provided they comply with certain guidelines. In either case we could see Quebec becoming 'separate' from the rest of Canada on this critically important issue.

#### **Conclusion**

In pondering medicine's possible involvement in euthanasia, we must foreground those aspects of the medical mandate that are immutable and eternally relevant. We believe these to be the constant nature of 'illness', changeless across time, place and culture, and the resultant obligations of the healer. It is important to appreciate how illness affects persons in all spheres of their lives. Patients become intensely vulnerable, impressionable and open to abuse. Pellegrino has summarized the nature of the clinical encounter eloquently as 'a peculiar constellation of urgency, intimacy, unavoidability, unpredictability and extraordinary vulnerability within which trust must be given'. 57 This vulnerability sets up an intense and enduring obligation of physicians; they must respond to the wounded person with authenticity, compassion and moral agency. The latter demands that physicians harness and deploy their unique influences and persuasive powers in a particular manner. The essential nature of physicianship has evolved over time in a direction that recognizes the extraordinary vulnerability of patients and guards ferociously against their exploitation. In part, this has been achieved by imposing inviolable limits on the physician's terrain of action. Moreover, we believe that, even if one accepted that euthanasia was ethically acceptable—which we do not—it opens up too many doors for abuse.

The medical profession has arrived at a crossroad; it must choose whether to embrace euthanasia as medical treatment, as a logical extension of end-of-life care, or it can reject the redefinition of its healing mandate that this would entail. We believe, that looking back in the future, the euthanasia events of the present time will be seen as a turning point, not only for the profession of medicine, but also for societies. Crossing the line in the sand articulated by Hippocrates, that as a physician 'I will neither give a deadly drug to anybody if asked for it, nor will I make a suggestion to this effect', would result in the 'doctor as healer' becoming the 'doctor as executioner'. In short, healing and euthanizing are simply not miscible and euthanasia can never be considered 'medical treatment'.

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# Exposing Vulnerable People to Euthanasia and Assisted Suicide

Alex Schadenberg
Foreword by Kevin Andrews

Connor Court Publishing
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For those who view euthanasia as a simple decision to end pain, Alex Schadenberg's book on the subject is a must read. He outlines very clearly any law covering this life and death decision is open to abuse more than most pieces of legislation. The dangers are out there for anyone who wishes to take a look.

#### Bernie Finn MLC, Victoria

Highlighting the reality of vulnerable citizens (elderly, disabled and depressed) dying, having lost the protection previously offered by the state, Schadenburg shows that the safeguard promises of euthanasia proponents haven't protected the community and cannot. They are merely promises made without concern for their keeping, by those who want to fundamentally experiment with the most basic laws against homicide.

#### Michael Ferguson MP, Tasmania

The case for legalising euthanasia collapses once it is exposed to careful scrutiny. Alex Schadenburg's detailed and clear examination of recent studies from Belgium is an invaluable addition to the toolbox of any compassionate legislator or citizen committed to protecting the vulnerable members of our communities by ensuring laws prohibiting murder or assisting a suicide are not eroded in the name of a false compassion. The publication of an Australian edition of this work is timely given the indefatigable efforts of euthanasia enthusiasts in introducing legalisation bills in parliaments across the nation. The insights given in this publication explaining how legalised euthanasia plays out in practice will help persuade legislators to defeat such bills and better understand why they ought never sanction the killing of the very citizens they represent.

#### Hon. Nick Goiran MLC, Western Australia

Alex Schadenberg has shown a great passion for educating legislators on issues surrounding euthanasia and assisted suicide. His informative publications and speeches have encouraged many Members of Parliament and Government to consider these issues more closely, and with a balanced and educated view.

#### Leesa Vlahos MP, South Australia

So-called progressive and liberal minded members of parliament in Australia and elsewhere continue to press for euthanasia/physician-assisted suicide legislation, claiming that legislatures can create such laws that are safe, that cannot be abused, and will not become the thin end of the wedge. In this small volume Alex Schadenberg brings together both information and data that should cause euthanasia/physician-assisted suicide advocates not just to pause, but step back from their positions. I do hope that this book receives wide readership in the general community.

#### Hon. Greg Donnelly MLC, New South Wales

Alex Schadenberg's comprehensive analysis of studies from countries where euthanasia is legal reveals disturbing evidence of inaccurate and misleading conclusions. He uncovers proof that vulnerable people, including the elderly, the depressed and those with disabilities, are very adversely affected when assisted suicide is legalised. His findings also raise significant concerns about the manipulation and abuse of the reporting process and the 'slippery slope' reality of state sanctioned intentional killing. This book spells out the chilling consequences and I would reommend it as required reading for legislators and commentators who may be contemplating changing our laws.

#### Maggie Barry MP, New Zealand

Using already existing studies, Schadenberg has uncovered the shocking truth about euthanasia in Belgium, the lives lost and the deep threat to others. His work demonstrates unequivocally that we must never follow this Belgian pathway to the easy killing of people whose lives are not valued by those who do the killing.

#### Kevin Fitzpatrick, Not Dead Yet, UK

Alex Schadenberg has done the debate on euthanasia and assisted suicide a great service in this comprehensive work. His thorough-going analysis of the available studies concerning The Netherlands and Belgium demands a response from those who support euthanasia & assisted suicide. This work supports empirically the observation that no legislation can ever protect all citizens from the possibility of abuse. For legislators and commentators alike, this is a must read.

#### Paul Russell, Founder of HOPE Australia

My friend was diagnosed with pancreas cancer in 2011. He had to turn down three independent euthanasia suggestions by his attending physicians. The suggestions were against our liberal euthanasia laws. It proves our societies are indeed on "a slippery slope" as argumented in this study; it's high time to wake up, we may already have passed the point of no return. Schadenberg's conclusive remarks therefore should be taken seriously.

#### Michael van der Mast, Cry for life - the Netherlands

#### **Foreword**

#### The Hon Kevin Andrews MP

Shortly after my admission to practice as a barrister-at-law, I was briefed to act in the case of an infant who had been born with Spina Bifida.

My clients, the grandparents of the child, observed that the new baby appeared to have been sedated and placed on demand feeding. They noted, over a couple of days, that the child was not drinking, and were concerned enough to seek advice.

After receiving their instructions, I sought an urgent interim injunction in the Supreme Court to require the hospital to do what was necessary to care for and maintain the life of the child until the case could be examined properly. The injunction was granted late one evening, and served on the hospital shortly afterwards.

Over the next few days, the Court considered the matter. When the judge expressed his surprise about the course of action allegedly being taken by the hospital, and an independent specialist found that the child had only mild Spina Bifida and should go on to lead a fulfilling life, the hospital lost interest in opposing the injunction.

The case was my first encounter with euthanasia. At the time, an annoyed medical practitioner advised me that there were many more such cases, and I was interfering with the hospital routine!

For years the proponents of euthanasia have rejected the argument of a 'slippery slope' – the belief that once legalized, euthanasia will be administered to many people who are neither consulted nor aware of the decision to hasten their death. We are regularly assured that laws can be crafted to avoid such abuse.

The reality is that euthanasia laws are sufficiently vague that such assurances are worthless. Further, the only person who may have a different intent is dead. Finally, prosecutors are reluctant to divert scare resources to investigate these cases.

The result, as the analysis in this book confirms, is the practice of euthanasia on many people who neither request it nor are aware of the decision. At a time when palliative care is widely available, and pain relief greatly enhanced, this is unacceptable.

If a law is to be valid, it must protect vulnerable people. Regrettably, euthanasia laws fail this basic test.

My initial encounter with euthanasia involved an infant. Most of the unknowing victims of euthanasia in The Netherlands and Belgium, where euthanasia has been legalized, are elderly.

The idea that there are lives unworthy to be lived is dangerous. The 'slippery slope' is not imaginary. It exists – and despite the efforts of euthanasia sympathizers – it cannot be wished away.

#### Background

In the past few years, several reports have been written by euthanasia proponents claiming that vulnerable patient groups are not adversely affected by legalising euthanasia or assisted suicide. These reports have concluded that there is no evidence that vulnerable people are threatened by legalising euthanasia or assisted suicide and there is no evidence of a "slippery slope."

This document is a response to these reports and to the key characteristics they share in common. I will demonstrate that:

- *i.* The studies used to determine that there is no proof that vulnerable patient groups are negatively affected by the legalisation of euthanasia are based on a pre-conceived outcome rather than openly considered the issues.
- *ii.* The conclusions of these studies are based on selective data.
- *iii.* When one analyses the data concerning euthanasia deaths without request and the unreported euthanasia deaths, one comes to a different conclusion.

This book proves that the conclusions of the Royal Society of

Canada End-of-Life Decision Making report, the Quebec government Select Committee on Dying with Dignity report, the Commission on Assisted Dying in the UK and the decision by Justice Lynn Smith in Carter v. Attorney General of Canada are false and misleading. The studies that these reports base their conclusions upon are not supported by the data.

#### The Terms of Reference

Euthanasia is an action or omission of an action that is done to directly and intentionally cause the death of another person to end suffering. Euthanasia is a form of homicide that is usually done by lethal injection. To legalise euthanasia, a nation would be required to create an exception to homicide in its criminal code. It is sometimes referred to as "Mercy Killing."

Assisted suicide is a death in which one person aids, counsels or encourages another person to commit suicide. Assisted suicide usually occurs when a physician prescribes a lethal dose to a person, knowing that the person intends to use the lethal dose for the purpose of suicide. It is sometimes referred to as physician-prescribed suicide.

Euthanasia and assisted suicide are similar since both require another person to be directly and intentionally involved with causing the death of another person. However, euthanasia and assisted suicide differ based on who completes the act.

Euthanasia and assisted suicide are direct and intentional. Therefore, the proper use of large doses of pain-killing drugs (analgesics), the proper use of sedation techniques oriented to eliminating pain and the withdrawing of medical treatment do not constitute euthanasia or assisted suicide.

In Canada, and many other countries such as Australia, New Zealand, France and the United Kingdom (UK), there is a strong societal debate occurring concerning the legalisation of euthanasia. In the United States there is a societal debate occurring concerning the legalisation of assisted suicide.

#### Nature of the Research:

This document will prove that if a researcher only focuses on the data from the reported euthanasia deaths or the "official statistics," it will appear that vulnerable groups are not adversely affected by the legalisation of euthanasia. It will also appear that there are very few, if any, problems with the implementation of euthanasia laws and no fear of a "slippery slope."

If a researcher analyses the unreported cases of euthanasia or the euthanasia deaths that are done without explicit request, in Belgium, then the research uncovers proof that vulnerable patient groups are adversely affected by the legalisation of euthanasia or assisted suicide.

The studies from Belgium also uncover other abuse of the euthanasia procedure, such as euthanasia by nurses, little protection for depressed people or people with mental illness, et cetera.

The abuse that occurs with the implementation of euthanasia that the studies uncover shows that statements such as: there are no fears of a "slippery slope" are false or misleading at best.

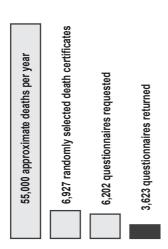
#### Document On e

### Medical End-of-Life Practices under the Euthanasia Law in Belgium

New England Journal of Medicine, September 10, 2009<sup>2</sup>

This article summarises a larger study concerning the practice of euthanasia and other medical end-of-life practices in Belgium. The article also reports on the rate of euthanasia deaths without an explicit request and the practice of deep- continuous sedation in Belgium.<sup>3</sup>

This is the first of three articles that are based on data from death certificates in the Flemish region of Belgium, a region with

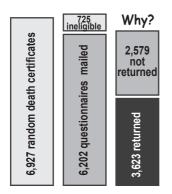


approximately six million people, representing 55,000 deaths per year. A random sample of 6,927 deaths from June 1-November 30, 2007, were studied. A five-page questionnaire was sent to the certifying physician in each death to determine what occurred.

3,623 questionnaires were returned and no response was possible for 725 of the questionnaires, leaving a 58.4% response rate (3,623 of the 6,202 valid cases).<sup>4</sup> This article establishes the

demographic group for those who die by euthanasia. The article states:

We found no shift in the characteristics of patients whose death was the result of euthanasia (mostly younger patients with cancer, or patients dying at home) ... the characteristics of whom lethal drugs (euthanasia) were used without request or consent (mostly older, incompetent patients), patients with cardiovascular diseases or cancer; or patients dying in hospitals).<sup>5</sup>



The article determined that a significant number of euthanasia deaths occur in Belgium without explicit request. The article stated: "In 1.8% of all deaths, lethal drugs were used without the patient's explicit request."

Those who die by euthanasia without explicit request represent a

different demographic group than those who die by euthanasia with explicit request.<sup>7</sup>

The article found that in 14.5% of all deaths in 2007 in Belgium, physicians reported using deep-continuous sedation until death, which represented an increase from a rate of 8.2% of all deaths from a study in 2001.8

Deep-continuous sedation is usually done by sedating a person and then withdrawing all medical treatment and care including hydration and nutrition. It is sometimes referred to as terminal sedation.

Deep-continuous sedation can be ethically the same as euthanasia when it is done with the intention of causing the death of a person who is not otherwise dying, and when the cause of death is intentional dehydration. A study published in *The Lancet*, entitled "Trends in end-of-life practices before and after the enactment of the euthanasia law in the Netherlands from 1990 to 2010: a repeated cross-sectional survey," concerns end-of-life practices in the Netherlands. This study found that the practice of deep-continuous sedation has risen dramatically since euthanasia became officially legal in the Netherlands in 2002. The study determined deep-continuous sedation was related to all deaths 5.6% of the time in 2001, 8.2% of the time in 2005 and 12.3% of the time in 2010 in the Netherlands.<sup>10</sup>

Therefore, Belgium and the Netherlands have both experienced a significant increase in the rate of deep-continuous sedation since the legalisation of euthanasia.

#### Conclusion

This article is the first to state that a different demographic group exists for those who die by euthanasia without an explicit request than people who die by euthanasia with request.

People who die by euthanasia without an explicit request are "mostly older, incompetent patients; patients with cardiovascular diseases or cancer; or patients dying in hospitals."<sup>11</sup>

People who die by euthanasia with an explicit request are "mostly younger patients, patients with cancer or patients dying at home." <sup>12</sup>

The article concluded:

We found that the enactment of the Belgium euthanasia law was followed by an increase in all types of medical end-of-life practices. ... However, the substantial increase in the frequency of deep sedation demands more in-depth research.<sup>13</sup>

Similar to the Netherlands, the massive increase in use of deep-continuous sedation suggests that it may be abused. The abuse of deep-continuous sedation needs to be further studied.

#### Document Two

#### Physician-Assisted Deaths Under the Euthanasia Law in Belgium: A Population-Based Survey

Canadian Medical Association Journal, 15 June 2010<sup>14</sup>

A random sample of 6,927 deaths from June 1 to November 30, 2007 were analysed within the study. The researchers sent a five-page questionnaire to the certifying physician in each of the deaths to determine what occurred. The researchers received 3,623 responses, while no response was possible for 725 of the questionnaires, a 58.4% response rate. 15

This study is the second of three articles based on data from death certificates in the Flanders region of Belgium. Based on the 3,623

# 208 Reported Assisted Deaths 5 Ass't Suicide 137 Euthanasia 6 Other 14 Dementia 46 Comatose

responses, the researchers identified that there were 137 euthanasia deaths, 5 assisted suicide deaths and 66 assisted deaths without explicit request. Therefore there were 208 assisted deaths with 66 (32%) of the assisted deaths being done without explicit request.

The study indicated that most of the people who die without explicit request were

not competent. The study stated:

66 Not Requested

142 Requested

Where the decision had not been discussed with the patient, the physician specified as reason(s) that the patient was comatose (70.1% of the cases) or had dementia (21.1% of the cases); in 40.4% of the cases, the physician indicated that the patient had previously expressed a wish for ending life (not equivalent to an explicit request for euthanasia).<sup>17</sup>

Therefore, most of the euthanasia deaths without explicit request were done to people who did not and could not request euthanasia at the time of death.

The study indicated that euthanasia without explicit request was only discussed with the patient in 22.1% of the cases. <sup>18</sup> Some of the reasons physicians did not discuss euthanasia with the patients were: 17% of the time the physician thought it was in the best interest of the patient, while 8.2% of the time the physician thought the discussion itself would have been harmful. <sup>19</sup>

The study found that euthanasia with request was most often done to alleviate pain or to fulfill a wish to end life.<sup>20</sup> Euthanasia without explicit request was most often to reduce the burden on the family or because they did not want to needlessly prolong the life of the patient.<sup>21</sup>

#### The demographic group of patients euthanased without explicit request "fits the description of vulnerable patient groups ..."

Another difference between euthanasia with an explicit request and euthanasia without an explicit request was the length and goal of treatment. People who died by euthanasia with request were, on average, receiving treatment for their illness for more than six months and the goal of treatment in the last week of life was comfort care and not cure. People who died by euthanasia without an explicit request, on average, received treatment for one month; and they were more likely to have had a cure as their goal of treatment in the last week.<sup>22</sup>

Euthanasia with request was most often done by barbiturate and muscle relaxant. Euthanasia without explicit request was usually done by intentional overdose of opioids, giving a level higher than needed to alleviate the patient's symptoms.<sup>23</sup> The article also stated that nurses were more often involved in the administration of the drugs with euthanasia without explicit request.<sup>24</sup>

The research team found that the demographic group of persons who died by euthanasia with request in comparison to euthanasia without explicit request was different. The study states:

Our finding that euthanasia and assisted suicide were typically performed in younger patients, patients with cancer and patients dying at home is consistent with findings from other studies. Our finding that the use of life-ending drugs without explicit patient request occurred predominantly in hospital and among patients 80 years or older who were mostly in coma or had dementia fits the description of "vulnerable" patient groups at risk of life-ending without request.<sup>25</sup>

In their conclusion, the authors stated:

Our study showed that physician-assisted death with an explicit request from the patient (euthanasia and assisted suicide) and use of life-ending drugs without an explicit request were different types of end-of-life decisions that occurred in different patient groups and under different circumstances. Unlike euthanasia and assisted suicide, the use of life-ending drugs without an explicit patient request often

involved patients with diseases other than cancer, which have an unpredictable end-of-life trajectory.<sup>26</sup>

Previous studies in Belgium concerning the characteristics of reported euthanasia deaths described the demographic for euthanasia as:

Men, younger patients, and cancer patients were significantly over-represented in euthanasia cases. Patients of 80 years or more were under-represented in all places of death among cancer and non-cancer patients.<sup>27</sup>

This study found that euthanasia without request represented a different demographic group from those who died by euthanasia with an explicit request. The study stated that for euthanasia deaths without an explicit request:

most involved patients who were 80 years of age or older (52.7%), those without cancer (67.5%) and those who died in hospital (67.1%).<sup>28</sup>

This fact that euthanasia deaths with request represented a different demographic group than euthanasia deaths without explicit request is important. Research reports that have been written by pro- euthanasia authors claim that there is no sign of risk for vulnerable groups in jurisdictions where euthanasia is legal.29

Previous studies did not include euthanasia deaths without request within their statistics because these deaths are less likely to be reported as compared to euthanasia deaths with request.<sup>30</sup>

#### Conclusion

People who die by euthanasia without explicit request are often incompetent to make medical decisions. The person often has chronic conditions where the end-of-life trajectory is unknown. It is the opinion of this author that physicians and nurses are, at times, reacting to pressure from families to "get on with the death" and they are reacting to pressures from the health care institution to contain costs by dealing with the problem of the "bed blocker."

The demographic group for those who die by euthanasia by request is a different demographic group of people from those who die by euthanasia without an explicit request. This demographic group "fits the description of vulnerable patient groups at risk of life-ending without request."<sup>31</sup>

#### Document Three

# The Role of Nurses in Physician- assisted Deaths in Belgium

Canadian Medical Association Journal, 15 June 2010<sup>32</sup>

The purpose of this study was to examine the involvement of nurses in Flanders, Belgium, in the decision-making, the preparation, and in the administration of life-ending drugs with or without a patient's explicit request in Flanders, Belgium.<sup>33</sup>

This study was the second phase of a two-phase study conducted between August and November 2007. The first phase of the study involved 6,000 nurses in Flanders, Belgium who were asked their attitudes towards life-shortening end-of-life decisions. The response rate for the first phase of the study was 63%. In that survey, the researchers assessed the experience with end-of-life shortening in the past 12 months.<sup>34</sup>

The second phase of the study analyzed the results of the first phase and determined that 1,678 nurses fit the criteria for the second phase of the study. Between November 2007 and February 2008, the research team sent questionnaires with letters of support from two major professional nursing organisations to the 1,678 nurses. Confidentiality was ensured and all data was processed anonymously.<sup>35</sup>

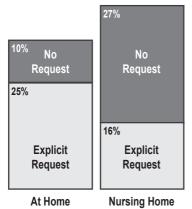
Ten of the 1,678 questionnaires were returned as undeliverable

and of the remaining 1,668, 1,265 of the questionnaires were returned as completed, representing a response rate of 76%.<sup>36</sup>

The responses from the questionnaire determined that 248 nurses reported that the last patient in their care died by euthanasia. Almost half (120 nurses) reported that the last patient in their care died by euthanasia without explicit request.<sup>37</sup> The study begins by stating:

In Belgium, the law permits physicians to perform euthanasia under strict requirements of due care, one of which is that they must discuss the request with the nurses involved.<sup>38</sup>

#### Nurses Administring Euthanasia



The law in Belgium does not permit nurses to carry-out the act of euthanasia or to assist a suicide.<sup>39</sup>

Nurses who worked in a home care setting were more likely to be involved in cases of euthanasia with explicit request (25%) than cases of euthanasia without explicit request (10%). Nurses who worked in care

homes (nursing homes) were more likely to be involved with cases of euthanasia without explicit request (27%) as opposed to euthanasia with explicit request (16%).<sup>40</sup>

This study also determined that people who died by euthanasia with request were more likely to be under the age of 80, to have cancer and to die at home. In contrast, people who died by euthanasia

without explicit request were more likely to be over the age of 80, were less likely to have had cancer and were more likely to die in a hospital.<sup>41</sup> These findings are the same as the findings in the study "Physician-assisted deaths under the euthanasia law in Belgium: a population-based survey" that found that 32% of all euthanasia deaths in the Flanders region of Belgium were done without explicit request.<sup>43</sup>

In cases where the patient died by euthanasia with explicit request, the patient had expressed their wish to the nurse 69% of the time, and the nurse reported being involved in the decision-making process 64% of the time. 40% of the nurses were involved in the preparation of the lethal dose, 34% of the nurses were present when the lethal dose was injected, and 31% of nurses provided support to the patient, the relatives, the physician or a fellow nurse.<sup>44</sup>

In cases where the patient died by euthanasia **without explicit request**, the patient had expressed their wish to the nurse 4% of the time, and the nurse reported being involved in the decision-making process 69% of the time. 48% of the nurses were involved in the preparation of the lethal dose, 56% of the nurses were present when the lethal dose was injected, and 51% of nurses provided support to the patient, the relatives, the physician or a fellow nurse. 45

## The lethal dose was injected by the nurse 12% of the time, even though this is illegal.

Euthanasia with request is often, but not always, discussed with the nurse; whereas euthanasia without explicit request was rarely discussed with the patient.

The nurses are more likely to be directly involved in euthanasia

when it is done without explicit request.

The lethal dose was injected by the nurse 12% of the time, even though this is illegal. The study stated:

"The drugs were administered by the nurse in 14 (12%) of the cases of euthanasia. The physician was not co-administrator in 12 of the 14 cases, but the drug was always given on his or her orders. The nurse administered neuro-muscular relaxant in four cases, a barbiturate in one case and opioids in nine cases. In nine cases the physician was not present during the administration of drugs."

The study also stated that the factors that were significantly associated with the nurse administering life-ending drugs were "the absence of an explicit request from the patient, the patient being more than 80 years old and the nurse having had a recent experience with life-shortening end-of-life decisions."<sup>47</sup>

The study indicated other factors were associated with the nurse administering life-ending drugs:

[F]emale nurses working in hospitals were six times and male nurses working in hospitals were forty times more likely than their male and female counterparts working in other settings to administer the life-ending drugs.<sup>48</sup>

Therefore, nurses who have administered a euthanasia death are more likely to do it again and male nurses are far more likely to administer a lethal dose than female nurses.

#### 45% of euthanasia deaths administered by nurses were done without explicit patient request

## **Important Concerns**

The administration of life-ending drugs by nurses whether or not it is under the physicians' responsibility is not legal under the Belgian euthanasia law. This study found that the nurse injected the lethal dose into the patient in 12% of the euthanasia deaths that they were involved in and 45% of the euthanasia deaths were without explicit request.<sup>49</sup>

It must be noted that phase one of the study entitled "Attitudes of nurses toward euthanasia and towards their role in euthanasia: a nationwide study in Flanders Belgium" found that of the 6,000 nurses who participated, 57% of the nurses accepted using lethal drugs for patients who suffer unbearably and are not capable of making decisions.<sup>50</sup>

The study indicated that the law is not being followed. The study stated:

It seems that the current law (which does not allow nurses to administer the life-ending drugs) and a control system do not prevent nurses from administering life-ending drugs.<sup>51</sup>

The study acknowledged its limitations:

Our study is possibly limited by selection bias, a reluctance of respondents to report illegal acts, the self-reported nature of the data and the lack of information from attending physicians or about the doses of drugs used.<sup>52</sup>

The study found that nurses are acting outside of the law. The study states:

By administering life-ending drugs at the physician's request in some cases of euthanasia, and even more so in cases without an explicit request from the patient, the nurses in our study operated beyond the legal margins of their profession.<sup>53</sup>

The study warns that actions outside of the law could cause nurses problems:

In particular, when criteria for due care are not fulfilled, such as in cases where the patient has not made an explicit request, nurses, next to the physician, risk legal prosecution. Nurses may get caught in a vulnerable position between following a physician's orders and performing an illegal act.<sup>54</sup>

Physicians in Belgium are required to report every euthanasia case. This study, regarding a previous study, concluded:

In a study of all cases of euthanasia in Belgium, "Legal Euthanasia in Belgium: Characteristics of All Reported Euthanasia Cases," *Journal of Medical Care*,<sup>55</sup> Smets and colleagues found that physicians did not always report their cases and that unreported cases often involved the use of opioids and the administration of them by nurses.<sup>56</sup>

#### Conclusion

Nurses in Belgium are participating in euthanasia with or without explicit consent, which is not legal under the Belgian euthanasia law. Even though nurses are usually not acting on their own, they are not discussing the decision with the patients.

Similar to the other studies, this study found that the demographic group that is dying without explicit consent is a different from the demographic group that dies with explicit consent.

### Document Four

# Researchers Respond to the Study "Role of Nurses in Physician-Assisted Deaths in Belgium"

Canadian Medical Association Journal, 23 June 2010

The fourth document analysed is a challenge to the study entitled "The role of nurses in physician-assisted deaths in Belgium" <sup>57</sup> and the response by one of the authors of the study, defending the conclusion of the study. <sup>58</sup>

On 23 June 2010, the *Canadian Medical Association Journal* published "A Response to 'The role of nurses in physician-assisted deaths in Belgium,'<sup>59</sup> by Dr. Victor Cellarius, Temmy Latner Centre for Palliative Care, Mount Sinai Hospital, Toronto.'<sup>60</sup>

Dr. Cellarius questioned whether the conclusion from the study "The role of nurses in physician-assisted deaths in Belgium" was accurate. Cellarius questioned that nearly half of the assisted deaths were done without explicit consent. He stated:

[T]he article shows in tabular form that of the "unexplicitly requested" assisted deaths, nurses discussed the patient's or relatives' wishes in 41% of cases when they were involved in decision-making – why is this not mentioned in the text? In the other cases was the doctor involved? Or others? The nurse answering the questionnaire may not have known, but the interpretation suggested (or at least made by many) seems to be that no discussion was had. The article makes several important claims that describe evasion or overlooking of law and policy, but the most startling suggestion – that half

of cases of assisted death are without consent – is the least supported. On this ground the article should be faulted for not making clear that the evidence does not permit such an interpretation.<sup>61</sup>

On 30 June 2010, the *Canadian Medical Association Journal* published the "Response to Victor Cellarius, i.e., The role of nurses in physician-assisted deaths in Belgium, Els Inghelbrecht, End-of-Life Care4 Research Group, Vrije Universiteit Brussell," 62 in which Dr. Inghelbrecht stated:

In our article it is stated that half of cases of assisted death are performed without the patient's explicit request. This is very much supported by the data in the article. There was patient consent or a wish from the patient in some of these cases, but in the administration of life-ending drugs this is legally not a sufficient reason. Furthermore a request or wish from relatives acting as surrogate decision-makers is equally regarded as insufficient to justify such acts. ... The focus of our article was explicitly on the role of nurses in decision-making and in the preparation and administration of life-ending drugs in case of assisted death with and without explicit patient request. Our questionnaire indeed asked whether there was discussion between the nurse and the relatives in those cases - which happened in 68.9% - but we did not include this in our article because involving the relatives, especially in case of patient incompetence, is ultimately the responsibility of the physician, as is the decision itself. The decision is not made between nurses and relatives, but by the physician with input from relatives as well as nurses.63

#### Conclusion

The communication between Inghelbrecht and Cellarius confirms that the conclusion of the study that indicated 120 of 248 assisted deaths that nurses were directly involved with were done without explicit request is, in fact, accurate.

The communication also confirms that nurses are actually carrying out acts of euthanasia, and this is outside of the legal practice of euthanasia in Belgium.

With respect to communication, Inghelbrecht confirmed that 68.9% of the time the relatives discussed the decision to cause death, but Inghelbrecht emphasised that this does not constitute an explicit request; and in Belgium, only physicians and not nurses have the responsibility to make such a decision.

#### Document Five

# Reporting of Euthanasia in Medical Practice in Flanders Belgium: Cross Sectional Analysis of Reported and Unreported Cases

British Medical Journal, November 2010<sup>64</sup>

This study concerns the reporting of euthanasia in the Flanders region of Belgium under the euthanasia law. It is the third of three studies based on data from death certificates in the Flanders region of Belgium. A random sample of 6,927 deaths from June 1 to November 30, 2007 was analyzed within the study. A five-page questionnaire was sent to the certifying physician in each of the deaths to determine what occurred. The researchers received 3,623 questionnaires while no response was possible for 725 of the questionnaires leaving a 58.4% response rate (3,623 of the 6,202 valid cases). 65

Based on the responses from the 3,623 questionnaires, the study concluded 52.8% of the euthanasia deaths in the Flanders region of Belgium were reported, while 47.2% of the euthanasia deaths were unreported.<sup>66</sup>

# "... concerns exist that only cases of euthanasia that are dealt with carefully are being reported."

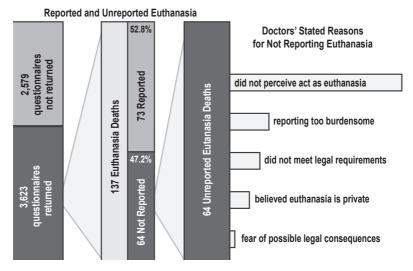
The study offers significant explanation into why euthanasia deaths are not being reported. The study found that the unreported

euthanasia deaths were significantly different than the reported euthanasia deaths. The study stated:

According to these documents, physicians who reported cases practised euthanasia carefully and in compliance with the law, and no cases of abuse have been found. However, concerns exist that only cases of euthanasia that are dealt with carefully are being reported.<sup>67</sup>

The following reasons were offered by the doctors for not reporting a death as euthanasia:

For 76.7% of the cases, physicians answered that they did not perceive their act as euthanasia, whereas for 17.9% they gave the reason that reporting is too much of an administrative



burden, 11.9% that the legal due requirement had possibly not all been met, and 9% that euthanasia is a private matter between the physician and patient (8.7%). A small proportion (2.3%) did not report the case because of possible legal consequences.<sup>68</sup>

Similar to the Belgian study that determined that 32% of euthanasia deaths were without explicit request,<sup>69</sup> the unreported euthanasia deaths re-presented a different demographic group than the reported cases. The study stated:

However, in a bivariate analysis there was a significant relation between reporting of euthanasia and the patient's age, with deaths of patients aged 80 years or older reported significantly less often than deaths of younger patients. Cases were also reported less often when the time by which life was shortened was less than one week compared with when the life shortening effect was greater.<sup>70</sup>

The issue of whether or not physicians ensured that the "safeguards" were followed or that the "due care" criteria was maintained is important. When the death was reported as euthanasia, usually the safeguards or due care criteria were followed, but when the death was not reported the "rules" were often not followed.

The study found that the differences between reported and unreported cases of euthanasia were:

A verbal as well as a written request for euthanasia was present in 73.1% of all reported cases, whereas a legally required written request was absent in the majority (87.7%) of the unreported cases. In reported cases, the decision was always discussed with others, which was not always the case (85.2%) in unreported cases. Other physicians and care givers specialised in palliative care were consulted (97.5%) more often in reported cases than in unreported cases (54.6%). ... In reported cases of euthanasia the drugs were almost always administered by a physician (97.7%); in unreported cases, the drugs were often administered by a nurse alone (41.3%). 71

# "... in unreported cases, the drugs were often administered by a nurse alone ..."

This meant that the legal requirements for requesting euthanasia were met 73.1% of the time when the euthanasia death was reported. The legal requirements were met 12.3% of the time when the euthanasia death was unreported. A palliative care consultation was usually done when the euthanasia case was reported but a palliative care consultation was only done half the time when the euthanasia case was not reported. It is interesting that reported euthanasia cases were not always done by a physician, but more than half of the euthanasia deaths that were not reported were not done by a physician.

The strength of this study is based on the fact that the physicians self-reported the findings. A weakness in the study is that the findings were only based on the Flemish region of Belgium. It is believed that the French-speaking region of Belgium has a different attitude toward euthanasia than the Flemish region.<sup>72</sup>

The study offered several reasons for the high rate of unreported euthanasia deaths. The first being that the Flanders region of Belgium does not have a long-term experience with euthanasia, as compared to the Netherlands, who had a reporting procedure for many years before euthanasia was officially legalised in 2002.<sup>73</sup>

# "... such legislation alone does not seem sufficient ... to guarantee the careful practice of euthanasia"

Many physicians did not realise that injecting a lethal dose of opioids with the intention of causing death is euthanasia. This also explains the large number of unreported euthanasia deaths that are done by nurses, which is illegal under the Belgian euthanasia law. Nurses are often administer opioids for palliative care and therefore when the intentional lethal overdose is "covered-up" as palliative care, it is not surprising that nurses administered the lethal dose.<sup>74</sup>

A second reason the study offered for the high rate of unreported euthanasia was that the physicians are more comfortable with palliative care than euthanasia. The study stated:

To reduce ... cognitive dissonance, they may choose to use opioids or sedatives because these drugs are not normally associated with euthanasia. Research has also shown that this kind of life ending practice might be more psychologically acceptable to physicians than bolus injection.<sup>75</sup>

The researchers pointed out that since most of the unreported euthanasia deaths were done on people who appeared to be closer to death, the physician either felt under pressure to end the life of the patient or the physician felt that there was not enough time to go through the legal process.<sup>76</sup>

In response to the concern about time-frame or pressure, the authors of the study indicated that:

The physician may ... prefer to use opioids or sedatives because these drugs are more readily available and there is less control over their distribution than with neuromuscular relaxants. By disguising euthanasia as pain alleviation, physicians can proceed with the euthanasia process without having to comply with the stringent, and in their perception time consuming, procedures of the euthanasia law.<sup>77</sup>

To disguise euthanasia as palliative care relieves the physician of the requirement of reporting the death, but it also forgoes the safeguards that were intentionally built into the law.

Concerning the "safeguard" of the requirement to consult another physician, the study stated:

Consultation occurred in almost all reported cases, where as it occurred in only half of all unreported cases. This association was also found in the Netherlands, where the most important reason for not consulting was that the physician did not intend to report the case. Physicians who intend to report a case seem to consult another physician and comply with the other requirements of the law, whereas physicians who do not intend to report a case appear to consult a physician only when they felt the need for the opinion of a colleague. The consult appear to consult a physician only when they felt the need for the opinion of a colleague.

### The study concludes:

As such legislation alone does not seem sufficient to reach the goal of transparency ("total" or a 100% transparency seems to be a rather utopian ideal) and to guarantee the careful practice of euthanasia.<sup>80</sup>

# This study confirms that the reporting system in Belgium is insufficient to protect people from euthanasia.

#### Conclusion

This study shows that physicians are not reporting euthanasia deaths based on a few primary reasons. Often the physician does not consider the medical decision to constitute euthanasia. Other times, the physician never intended to report the death as euthanasia, and

sometimes the physician will not report the euthanasia death because it is outside of the parameters of the law.

# "... not one physician has faced prosecution for causing a death outside the parameters of the law."

Physicians who are not following the parameters of the law should be investigated by the Belgian Medical Association or prosecuted under the law. Smets et al., stated in the study "Legal Euthanasia in Belgium: Characteristics of All Reported Euthanasia Cases" that not one physician has faced prosecution for causing a death outside the parameters of the law.81

This study confirms that the reporting system in Belgium is insufficient to protect people from euthanasia. The reporting system is based on the physician voluntarily reporting the euthanasia death to the authorities. There is no procedure to ensure that all reports are sent in, and there is no assurance that the data that is sent into the authorities is accurate.

When a physician or nurse decides to cause the death of a patient in a manner which is outside of the parameters of the law, the way to "get away with it" is to not report it as a euthanasia death.

This study shows that vulnerable people die by euthanasia in Belgium and these deaths are not being reported, making it an invisible crime.<sup>82</sup>

This study shows that vulnerable people die by euthanasia in Belgium and these deaths are not being reported, making it an invisible crime. Any study or court decision that suggests that there is no indication that vulnerable groups are dying by euthanasia in jurisdictions where euthanasia and/or assisted suicide is legal is false. Data that is provided by the reporting procedures in the Netherlands, Belgium, Oregon and Washington State is limited. There are clear indications that vulnerable groups are at risk when euthanasia and/or assisted suicide are done outside of the law, and those cases are rarely reported.

### Document Six

# Comparing Belgium to the Netherlands: "Trends in end-of-life practices before and after the enactment of the euthanasia law in the Netherlands"

Lancet, July 201283

Similar to the previous cross-sectional studies that concerned the practice of euthanasia in the Netherlands during the years 2005<sup>84</sup>, 2001<sup>85</sup>, 1995<sup>86</sup>, and 1990<sup>87</sup>, the current meta-analysis compares 2010 to the previous studies and uncovers significant concerns related to euthanasia in the Netherlands.

It is important to compare the experience of legalised euthanasia in Belgium to that of the Netherlands because these countries both legalised euthanasia around a similar time and they both have similar euthanasia laws.

# The increase in the rate of unreported euthanasia deaths in the Netherlands confirms evidence documenting the practice in Belgium..

The study was done by mailing out 8,496 questionnaires to physicians to determine the frequency and their experience with euthanasia and assisted suicide. 6,263 of the questionnaires were returned and eligible for analysis (74% response rate).<sup>88</sup>

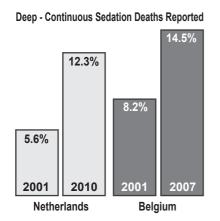
From 2005 to 2010 in the Netherlands, the percentage of unreported euthanasia deaths increased from 20% to 23%.<sup>89</sup> Even

though the Netherlands has trained consultants to improve the practice of euthanasia, the number of unreported euthanasia deaths has increased.

The increase in the rate of unreported euthanasia deaths in the Netherlands confirms the statement by the authors of the study "Reporting of euthanasia in medical practice in Flanders, Belgium: cross sectional analysis of reported and unreported cases," who concluded that: "100% transparency seems to be a rather utopian ideal."

# "100% transparency seems to be a rather utopian ideal"

The study determined that the demographic group for reported euthanasia deaths is: "mostly... younger people, cancer patients, and in general practice (in home) rather than in hospitals or nursing homes." This is the same demographic group for reported euthanasia deaths in Belgium. 92 The study did not report the demographic group for the unreported euthanasia deaths. In Belgium, the demographic



group for the unreported euthanasia deaths tended to be older.<sup>93</sup>

The report found that there were approximately 310 assisted deaths without an explicit request in the Netherlands in 2010<sup>94</sup>, which was down from an estimated 550 assisted deaths without an explicit request in

2005. In Belgium, the study "Physician-assisted deaths..." found that 32% of the euthanasia deaths in the Flanders region of Belgium were done without request or consent. 96

The fact that the number of deaths without explicit request has dropped in the Netherlands appears optimistic, unless you are one of the 310 people.

The percentage of deaths by euthanasia and assisted suicide in the Netherlands increased from 1.8% of all deaths in 2005 to approximately 3.0% in 2010.<sup>97</sup> The actual number of euthanasia and assisted suicide deaths increased from 2,425 in 2005 to 4,050 in 2010.<sup>98</sup>

At the same time, the number of deaths by deep-continuous sedation increased in the Netherlands from 8.2% of all deaths in 2005 to 12.3% of all deaths in 2010, representing a 50% increase. The rates of deep-continuous sedation are particularly concerning in both the Netherlands and Belgium. In Belgium, the article "Medical End-of-Life Practices under the Euthanasia Law in Belgium" found that the rate of continuous or deep-continuous sedation in Belgium increased from 8.2% of all deaths in 2001 to 14.5% of all deaths in 2007.

Deep-continuous sedation is important because it can be abused. Physicians can sedate a person with the intention of palliation, normally referred to as palliative sedation, or the physician can sedate a patient with the intention of causing death, which is often referred to as terminal sedation. Research needs to be done, comparing the average doses of drug used to palliate symptoms as compared to the average doses of drugs used in the Netherlands, Belgium, or other

jurisdictions, where the physician appears to intend to cause death.

Further data has recently become available. The 2011 Netherlands euthanasia statistics showed a continued increase in the rate of euthanasia. The number of euthanasia deaths in the Netherlands has increased by 18% in 2011, 19% in 2010 and 13% in 2009; and the number of euthanasia deaths in 2011 was more than double the number of euthanasia deaths in 2003. 100

The Netherlands' euthanasia statistics suggest that the rate of euthanasia will increase on a constant basis until it reaches a point whereby euthanasia is considered medically acceptable and it becomes normalised.

The Netherlands' and Belgium's statistics indicate that not all doctors will follow the guidelines in the law. After 9 years of legal euthanasia in the Netherlands, 23% of all euthanasia deaths continue to be unreported, 101 and up to 47% of all euthanasia deaths in Belgium are unreported. 102

The Netherlands did not publish the demographic data for the unreported euthanasia deaths; therefore, it is not possible at this time to show that vulnerable people are not adversely affected by the euthanasia law. It is also not possible to state that there is no evidence that vulnerable groups are adversely affected by euthanasia.

### Document Seven

# Legal Euthanasia in Belgium: Characteristics of All Reported Euthanasia Cases

Journal of Medical Care, February 2010<sup>103</sup>

This study examined every reported case of euthanasia in Belgium from September 22, 2002 to December 31, 2007. There were 1917 reported euthanasia deaths within that time-frame. 104

In Belgium, euthanasia is defined as the intentional ending of life by a physician at the explicit request of a patient on condition that all the due care requirements prescribed in the law are satisfied.<sup>105</sup>

Euthanasia in Belgium is not limited to terminally ill people and it is not limited to physical suffering, <sup>106</sup> but rather suffering alone. Suffering is undefined, unclear and based on personal and not objective criteria. Suffering can only be determined by the person requesting euthanasia. <sup>107</sup>

The Belgian law requires a physician to obtain consent for euthanasia from a person who is terminally ill or suffering. A person requesting euthanasia who is not terminally ill must receive approval by a physician, a specialist and a psychiatrist.<sup>108</sup>

The study indicated that all of the data was collected from reports that are submitted by the physician who does the act of euthanasia (required by law). The study stated:

Because of the anonymous nature of the notification

procedure, it was impossible to contact the reporting physician for more in-depth information, or to match the reported cases to the corresponding death certificates. <sup>109</sup>

The study acknowledged another weakness and stated: "Death certificate data for Wallonia were not available for this period." 110

The study recognised that it is possible that unreported euthanasia deaths might have different characteristics than reported euthanasia deaths. However, the study only considered reported euthanasia deaths. 111

The data from the study, "Reporting of euthanasia in medical practice in Flanders Belgium: cross sectional analysis of reported and unreported cases", found that only 52.8% of all euthanasia deaths were reported. Therefore 47.2% of all euthanasia deaths are not reported. 112

The research analysis overlooks the possibility that the data from the official reports may be inaccurate. The reports are received from the physician who carried out the act of euthanasia. The report is, therefore, based on a self-reporting procedure. Doctors, like all others, are not likely to self-report abuse of the law, especially since it is possible that euthanasia deaths that are done outside of the legal practice may be investigated. It is important to note that of the 1,917 reported euthanasia deaths, the Committee has never sent a reported case to the judicial authorities.

The study found that the number of euthanasia deaths increased every year since euthanasia was legalised. <sup>118</sup> In 2010, there were 954 reported euthanasia deaths in Belgium. <sup>119</sup> Since Smets, Tinne, et al., "Reporting of euthanasia in medical practice in Flanders Belgium: cross sectional analysis of reported and unreported cases", found

that only 52.8% of all euthanasia deaths were reported, <sup>120</sup> therefore the actual number of euthanasia deaths is much higher.

The study indicated that the demographic for the 1,917 reported euthanasia deaths was that "men, younger patients, and cancer patients were significantly over-represented in euthanasia cases. Patients of 80 years or more were under-represented in all places of death among cancer and non-cancer patients."<sup>121</sup>

The demographic for reported euthanasia deaths is similar to the demographic for reported euthanasia deaths in the Netherlands. 122

The study stated that "no evidence was found to support the fear that, once euthanasia is legalized, the lives of elderly patients would be more likely to be ended with assistance of a physician." We know from the other studies that this statement is false.

The study that found that 32% of all euthanasia deaths in the Flanders region of Belgium were done without explicit request<sup>124</sup> also indicated that the demographic group for unreported euthanasia deaths was "patients who were 80 years of age or older (52.7%), those without cancer (67.5%) and those who died in hospital (67.1%)". <sup>125</sup>

# ... of the 1917 reported euthanasia deaths, the Committee has never sent a reported case to the judicial authorities.

The study concludes, "Developments over time do not show any indication to support the slippery slope hypothesis." <sup>126</sup> The data from this study does not allow the researchers to definitively back-up this statement. The study indicates that there is a high number of euthanasia deaths without explicit request but it does not analyze the data from this group.

The study is based on data that is limited to reported euthanasia deaths alone; and other studies found that the reported euthanasia deaths were usually done according to the rules of the law while the unreported euthanasia deaths often did not follow the rules of the law.<sup>127</sup>

If we were to base our conclusions on this study alone, we would think that all is well with the practice of euthanasia in Belgium. When considering studies that examined data from the large number of unreported euthanasia deaths and euthanasia deaths that were done by nurses and the euthanasia deaths done without explicit request, then we come to a very different conclusion.

# Three Reports and One Court Decision That Have Drawn False or Misleading Conclusions

"Legal physician-assisted death in Oregon and the Netherlands: evidence concerning the impact on patients in 'vulnerable' groups", <sup>128</sup> The Journal of Medical Ethics (2007).

The Royal Society of Canada Expert Panel: End-of-Life Decision Making Report<sup>129</sup> seems to establish the foundation for the conclusions of subsequent reports in Canada.

The Quebec government's Select Committee on Dying with Dignity Report<sup>130</sup> concluded that euthanasia should be legalised in Quebec. It, too, influenced subsequent reports.

Justice Lynn Smith, in *Carter v. Canada* (Attorney General)<sup>131</sup> in British Columbia, decided that Canada's laws concerning euthanasia and assisted suicide are unconstitutional and over-broad.

These studies appear to be written with the intent of forming the basis for legalising euthanasia and assisted suicide in Canada and throughout the Western world.

# The First Report

The first study, "Legal physician-assisted death in Oregon and the Netherlands: evidence concerning the impact on patients in 'vulnerable' groups," was completed under the leadership of Margaret Battin (University of Utah). This study looked at the official statistics from the Netherlands and Oregon, and other studies from both jurisdictions, and concluded that in the Netherlands and the State of Oregon, where euthanasia and/or assisted suicide have been legalised, that there is no proof that vulnerable people (other than people who are dying from AIDS) are more likely to die by euthanasia or assisted suicide. It concluded that the concept of a "slippery slope" is unfounded, and other than people with HIV, and no other vulnerable group is adversely affected by the legalisation of euthanasia and assisted suicide.<sup>132</sup>

Battin came to her conclusion even though two studies from the Netherlands, which were published in 2004, indicated that euthanasia deaths that are reported tend to follow the guidelines but euthanasia deaths that are not reported tend not to comply with the guidelines. <sup>133</sup>

## The Second Report

The report of the Royal Society of Canada Expert Panel: End-of-Life Decision Making, November 2011, <sup>134</sup> concluded that Canada could "safely" legalise euthanasia and assisted suicide.

This report also concluded:

Despite the fears of opponents, it is also clear that the much-feared slippery slope has not emerged following decriminalisation, at least not in those jurisdictions for which evidence is available. Nor is there evidence to support the claim that permitting doctors to participate in bringing about the death of a patient has harmed the doctor/patient relationship. What has emerged is evidence that the law is capable of managing the decriminalisation of assisted dying and that state policies on this issue can reassure citizens of their safety and well-being. 135

The Royal Society of Canada Report came to its conclusion even though it pointed out that there were approximately 550 deaths without request (Lawer) in 2005 in the Netherlands, <sup>136</sup> and deaths without request in Belgium represented 1.8% of all deaths in 2007; the report admitted that the number of involuntary euthanasia deaths were nearly identical to the percentage of voluntary euthanasia. <sup>137</sup>

The data concerning the high rate of euthanasia deaths without explicit request in Belgium was reported in the article "Medical Endof-Life Practices under the Euthanasia Law in Belgium." This article was examined in The Royal Society of Canada Report. The article identified the concern related to unreported euthanasia deaths.

The question remains: Why did The Royal Society of Canada Report ignore the analysis of the data that was provided in the study by Smets called "Reporting of euthanasia in medical practice in Flanders Belgium: cross sectional analysis of reported and unreported cases"? That study found, that unreported euthanasia deaths were more likely to be done to people who were older<sup>138</sup> representing a vulnerable patient group.

The Royal Society of Canada appointed an expert panel dominated by euthanasia lobby activists including:

- Jocelyn Downie, author of Dying Justice: A Case for Decriminalising Euthanasia and Assisted Suicide in Canada<sup>139</sup>
- Sheila McLean, author of Assisted Dying: Reflection on the Need for Law Reform<sup>140</sup>
- Johannes J.M. van Delden, a long-time euthanasia promoter in the Netherlands, contributed to several reports on the practice of Euthanasia in the Netherlands.<sup>141</sup>

The acknowledgment at the beginning of The Royal Society of

Canada Report recognises several people for their help in the editing and production of the report including pro-euthanasia promoters:

- Dan Brock (Harvard)
- Helga Kuhse (Monash)
- Peter Singer (Princeton)
- Robert Young (La Trobe). 142

It would appear that the Royal Society of Canada End-of-Life Decision Making panel was created to be one-sided in order to produce a one-sided report. The panel did not appear to be interested in open debate on the issues but they appear to be imposing a specific point of view upon society.<sup>143</sup>

It also appears that the Royal Society of Canada Report drew false conclusions by limiting the scope of data.

But the problem did not end there. The Quebec commission founded its conclusions upon the Royal Commission report. The resulting Quebec National Assembly Dying with Dignity report reads like a "Euthanasia Manifesto" according to an article written by Margaret Somerville in the *Montreal Gazette*, 26 March.

## The Third Report

The Commission on Assisted Dying Report<sup>144</sup> in the United Kingdom (also known as Lord Falconer's Report on Assisted Dying) was made up of pro-assisted suicide activists, was sponsored by Dignity in Dying (formerly known as the Voluntary Euthanasia Society) and received its funding from euthanasia campaigner, Terry Pratchett.<sup>145</sup>

The Commission on Assisted Dying Report concluded that the United Kingdom needed to legalise assisted suicide with safeguards.

# The Legal Decision

In the Carter v. Attorney General of Canada decision, Justice Lynn Smith appeared to thoroughly examine the experience with euthanasia and assisted suicide in the jurisdictions where it is legal. With reference to Belgium, Smith analysed most of the pertinent studies and came to a false conclusion.

In the Carter decision, Paragraph 575 responds to a question related to disability. She states that Professor Deliens declared that in the questionnaire, which was sent to physicians, that there was no question concerning disability; however, Deliens concludes that they could determine from the death certificates whether a person had a disability. He stated that they found no cases of disability. <sup>146</sup>

This is an interesting conclusion considering the fact that many people have disabilities, especially later in life.

A questionable response by Justice Smith occurs when she looks at the question of euthanasia without request. She stated:

Finally, I note that Professor Deliens was asked about the comment in the Chambaere et al. Population Study that 'the use of life-ending drugs without explicit patient request occurred predominantly in hospital and among patients 80 years or older who were mostly in a coma or had dementia and fits the description of "vulnerable" patient groups at risk of life ending without request.'147

Smith responds to Professor Delien's evidence as follows:

His responses to this line of questioning suggested that possibly he did not wish to admit that he had said that patients who are 80 years or older are vulnerable and at risk of LAWER. I take into account that Professor Deliens was ill,

and was being cross-examined by videolink, in English (not his first language). Perhaps for those reasons, or perhaps because of a lack of impartiality, his responses in this one area did not seem wholly straightforward. <sup>148</sup>

The fact is that Deliens admitted that the Belgian research indicates that euthanasia deaths without request are more often done to a vulnerable patient group, as stated in the study "Physician-assisted deaths under the euthanasia law in Belgium: a population-based survey." Why did Justice Smith then ignore his comment by providing some excuse that he was sick?

# **Our Conclusions**

The conclusions of The Royal Society of Canada Expert Panel Endof-Life Decision Making Report, <sup>150</sup> and the Quebec government's Select Committee on Dying with Dignity Report <sup>151</sup> appear to be based on selective data from research that was limited to the official statistics from the reported euthanasia and/or assisted suicide deaths. These reports appear in their design to be intentionally oriented to establishing preconceived conclusions.

All of these reports, including the court decision by Justice Lynn Smith in *Carter v. Canada*, conclude that euthanasia in other jurisdictions, including Belgium, is occurring without threats to the lives of vulnerable groups. They further claim that there is no reasonable proof that a "slippery slope" exists.<sup>152</sup> This conclusion is false because it ignores all data that challenges this conclusion.

When examining the studies concerning the practice of euthanasia, the role of nurses and the reporting of euthanasia in Belgium, reasonable people must conclude that not all is well in Belgium.

The study "Medical End-of-Life Practices under the Euthanasia Law in Belgium" found that euthanasia deaths without request or consent represent a different demographic group than those who die by euthanasia with consent. 154

The study "Physician-assisted deaths under the euthanasia law in Belgium: a population-based survey" found that 32% of the euthanasia deaths in the Flanders region of Belgium were

done without explicit request.<sup>156</sup> This study determined that "the use of life-ending drugs without explicit patient request occurred predominantly in hospital and among patients 80 years or older who were mostly in coma or had dementia."<sup>157</sup> This study found that there is a different demographic group for people who die by euthanasia without explicit request. The researchers stated that this "fits the description of "vulnerable" patient groups."<sup>158</sup> The same study also stated that "in the group without an explicit request, most of the patients had diseases other than cancer, which have less predictable end-of-life trajectories."<sup>159</sup>

This is an important comment because it indicates that euthanasia is being done without an explicit request to control the timing of death.

The study "The role of nurses in physician-assisted deaths in Belgium" proves that nurses are directly causing the death of their patients in Belgium (euthanasia) which is not legal in that country.

The study also determined that "factors significantly associated with the nurse administering the life-ending drugs were the absence of an explicit request from the patient, the patient being more than 80 years old and the nurse having had a recent experience with life-shortening end-of-life decisions." <sup>161</sup>

Other factors associated with the nurse administering life-ending drugs were that "female nurses working in hospitals were six times and male nurses working in hospitals were 40 times more likely than their male and female counterparts working in other settings to administer the life-ending drugs." <sup>162</sup>

The study "Legal Euthanasia in Belgium: Characteristics of All Reported Euthanasia Cases," 163 which is referred to by the Royal

Society of Canada Report, determined the characteristics of the 1,917 reported euthanasia deaths in Belgium. However, this study does not include the unreported euthanasia deaths in Belgium within its analysis. Therefore, the analysis by The Royal Society of Canada Report is inaccurate and misleading.

The study "Reporting of euthanasia in medical practice in Flanders Belgium: cross sectional analysis of reported and unreported cases" found that the 52.8% of euthanasia deaths that were reported were usually done in accordance with the legal requirements, but the 47.2% of the euthanasia deaths that were not reported often did not follow the legal requirements. The same study also found that "there was a significant relation between reporting of euthanasia and the patient's age, with deaths of patients aged 80 years or older reported significantly less often than deaths of younger patients." 166

Physicians indicated that some of the reasons for not reporting these deaths as euthanasia were:

17.9% that reporting is too much of an administrative burden, 11.9% that the legal due requirement had possibly not all been met, 8.7% that euthanasia is a private matter between the physician and patient. A small proportion (2.3%) did not report the case because of possible legal consequences. 167

When the physician is concerned that the euthanasia death does not meet the legal criteria, they do not report the death as euthanasia.<sup>168</sup>

The same study determined that when the physician did not intend to report the death as euthanasia, that they usually did not consult another physician either. The authors stated: "This association was also found in the Netherlands, where the most important reason for not consulting was that the physician did not intend to report the case." <sup>169</sup>

The same study found that unreported euthanasia deaths were usually done by intentional opioid overdose. The study indicated:

The physician may ... prefer to use opioids or sedatives because these drugs are more readily available and there is less control over their distribution than with neuromuscular relaxants. By disguising euthanasia as pain alleviation, physicians can proceed with the euthanasia process without having to comply with the stringent, and in their perception time consuming, procedures of the euthanasia law.<sup>170</sup>

The authors of the study concluded that "legislation alone does not seem sufficient to reach the goal of transparency ('total' or a 100% transparency seems to be a rather utopian ideal)."<sup>171</sup>

This statement directly contradicts Justice Lynn Smith's comments in her *Carter v. Canada* decision whereby she attempted to assure Canadians that euthanasia could be effectively legalised with safeguards.<sup>172</sup>

When analysing the three Belgian studies concerning the practice of euthanasia, the role of nurses and the reporting of euthanasia in Belgium, one must conclude the following:

- When a physician in Belgium reports a euthanasia death, as euthanasia, the physician usually follows the rules that are outlined by the law.<sup>173</sup>
- 2. When a physician does not report a euthanasia death, as euthanasia, the physician will often not follow the rules that are outlined by the law.<sup>174</sup>
- 3. When a euthanasia death is not reported, the patient is more likely to be over the age of 80, die in a hospital, and is often

incompetent to consent to the act.<sup>175</sup> Euthanasia deaths that are done without explicit request are usually done to a person who is within the same demographic group. The same demographic is also over represented when a euthanasia death is done by a nurse. Therefore, euthanasia deaths that are done without explicit request, that are unreported, or that are done by nurses fit the same demographic group. This demographic group "fits the description of a "vulnerable" patient group."<sup>176</sup>

- 4. Reasons for not reporting a euthanasia death, as euthanasia, include the following: to avoid the administrative burden, to avoid the fact that the legal due requirements are not met and to avoid possible legal consequences. Often the physician never intended to report the death as euthanasia.
- 5. Euthanasia deaths that are done by nurses in Belgium are not legal but occur on a regular basis; these deaths are usually done by order of a physician, but sometimes they were done without consulting the physician. These deaths are usually done by intentional opioid overdose, even though sometimes they were done by neuromuscular relaxants, while 45% of the time they are done without explicit request. Nurses who had previously been involved with a euthanasia death and male nurses were far more likely to carry-out euthanasia in Belgium.

# The first person in Belgium who died of euthanasia followed by organ donation was disabled and not terminally ill.

There are many areas of concern related to the practice of euthanasia in Belgium. Studies have also indicated that doctors in Belgium are not required to do euthanasia, but that they are required to refer a patient for euthanasia.<sup>177</sup> Similar to the

Netherlands, Belgium considers euthanasia an option for people with dementia.<sup>178</sup> Belgium has also implemented rules related to euthanasia and organ donation.<sup>179</sup> In fact, the first person who died by euthanasia and organ donation was a person who was disabled and not terminally ill.<sup>180</sup>

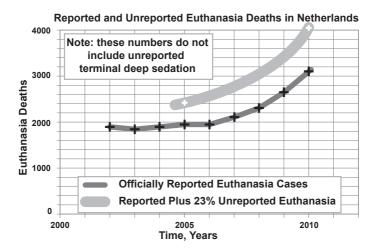
## Depression and Euthanasia

Another concern related to euthanasia and assisted suicide that the Belgium studies did not investigate is the effect of depression on vulnerable persons. A study by a Dutch oncologist, "Euthanasia and Depression: A Prospective Cohort Study Among Terminally Ill Cancer Patients," found that: "a request for euthanasia by patients with a depressed mood was 4.1 times higher than that of patients without a depressed mood." The study concluded: "Our findings suggest that a depressed mood in the last months of life is associated with a higher risk for request for euthanasia." <sup>182</sup>

A weakness in this study is that the authors did not include the number of people with a depressed mood who actually died by euthanasia.

A similar study, concerning depression which was done in the State of Oregon, entitled "Prevalence of depression and anxiety in patients requesting physicians' aid in dying: cross sectional survey" published in 2008 in the British Medical Journal found that of the 58 people who asked for assisted suicide and agreed to be part of the study, 15 were found to be depressed. <sup>183</sup> Of the 58 people in the study, 18 died by assisted suicide with 3 of them being among the group of depressed people. <sup>184</sup>

I do not know of a study concerning depression and euthanasia



in Belgium, but it is likely that the results from the Netherlands and Oregon State would be similar in Belgium.

## Increasing Numbers of Euthanasia Deaths

Another concern related to the implementation of euthanasia and assisted suicide laws is the growth over time in the number of deaths by euthanasia or assisted suicide. The study "Legal Euthanasia in Belgium: Characteristics of All Reported Euthanasia Cases" states that from 22 September 2002 to 31 December 2007, 1,917 euthanasia deaths were reported in Belgium. The study also indicates that the number of euthanasia deaths increased every year since euthanasia was legalised. In 2010, there were 954 reported euthanasia deaths in Belgium.

In the Netherlands, the number of reported euthanasia deaths has grown significantly in the past few years. The statistics concerning the number of reported euthanasia deaths in the Netherlands are as follows: 2006 - 1,923 deaths, 2007 - 2,120 deaths, 2008 - 2,331

deaths, 2009 - 2,636 deaths, 2010 - 3,136 deaths, and 2011 - 3,695 deaths. These statistics do not include the assisted suicide deaths or the unreported euthanasia deaths that in 2010 were estimated to be 23% of all euthanasia deaths in the Netherlands. 189

In Belgium, not one physician has faced prosecution for causing a death (euthanasia) outside the parameters of the law, <sup>190</sup> even though there is clear proof of each of the following: nurses are lethally injecting people, which is outside of the law; <sup>191</sup> euthanasia deaths are occurring without explicit request which is outside of the law; <sup>192</sup> as high as 47% of euthanasia cases are not being reported, which is outside of the law; <sup>193</sup> and a large number of the unreported euthanasia deaths occur without the physician ever intending to report the death as euthanasia. <sup>194</sup>

Those who support euthanasia and assisted suicide will often refer to the reporting procedure as a safeguard to ensure that the law is not abused. The reporting procedure for assisted suicide in the states of Oregon and Washington, where assisted suicide is legal, is very similar to the reporting procedure for euthanasia in Belgium and the Netherlands. All of these jurisdictions require the physician to report the euthanasia or assisted suicide death after the person has died; and the report is sent into the authorities by the doctor who caused the death, in the case of euthanasia, or by the doctor who wrote the prescription for the lethal dose, in the case of assisted suicide.

The reporting procedure in the Netherlands, Belgium, Oregon State and Washington State do not protect people from abuse because of the following:

1. The person has died already once the report is sent into the

- authorities. No protection is provided from abuse by an afterthe-death reporting procedure. You cannot reverse the act.
- 2. The study in Belgium, that stated that 32% of all euthanasia deaths were unreported, found that when a physician did not follow the guidelines in the law, or when the death was outside the parameters of the law, the physician usually did not report the death as a euthanasia death. It must be noted that the 2010 study from the Netherlands found that 23% of all euthanasia deaths went unreported.
- 3. If an abuse of the law occurs and the physician reports the euthanasia death, will the doctor self-report abuse?

When considering an issue of life and death, can a nation consider any level of intentional killings as acceptable? When considering that euthanasia concerns people who are die by lethal injection and assisted suicide occurs by intentional lethal overdose, can society ensure that every citizen will be safe?

To state that there are few, if any, concerns related to the practice of euthanasia in Belgium is clearly false, and to state that there are no indications of a "slippery slope" effect in Belgium is false and misleading.

The fact is that there has been a clear growth and an increased promotion of euthanasia and assisted suicide. Euthanasia and assisted suicide are becoming accepted for more and more reasons, and there are few effective controls to protect vulnerable people from it.

Society needs to ensure that every person is cared for and treated with dignity and it must limit its actions to non-lethal means to alleviate suffering. By exposing vulnerable people to euthanasia and assisted suicide the life that will be taken could include yours, your mother's, or that of someone who needs to be cared for and not to be killed.

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ALEX SCHADENBERG has been the executive director of the Euthanasia Prevention Coalition (EPC) since its founding in 1998. Alex is known for his research into issues related to euthanasia, assisted suicide and other end-of-life issues and concerns. This is the second book that has been written by Alex.

Alex's articles have been pub-lished throughout the world and his blog (www.alexschadenberg.blogspot.com) has become known as a definitive source of information on issues related to euthanasia and assisted suicide.

He is also a world renowned speaker and has spoken throughout Canada, the United States, Australia, New Zealand, Scotland, Switzerland and Italy.

In November 2007 he was chosen as the Chair of the Euthanasia Prevention Coalition-International, a coordinating body of groups that work to oppose euthanasia and assisted suicide.

Alex works with many other groups to establish an effective world-wide opposition to euthanasia and assisted suicide, such as: HOPE Australia, TAS, Choice is an Illusion, and the Care Not Killing Alliance.

Alex organised:

The First International Symposium on Euthanasia and Assisted Suicide (November 30-December 1, 2007) in Toronto Ontario.

The Second International Symposium on Euthanasia and Assisted Suicide (May 29-30, 2009) near Washington DC.

The Third International Symposium on Euthanasia and

Assisted Suicide (June 3-4, 2011) in Vancouver BC.

Alex also helped to organise:

The First European Symposium on Euthanasia and Assisted Suicide (Sept 7-8, 2012) in Edinburgh Scotland.

Alex is married to Susan and they have six children.

## **HOPE**

HOPE: preventing euthanasia & assisted suicide is a coalition of groups and individuals who oppose the legalisation of euthanasia and assisted suicide in Australia and support measures that will make euthanasia and assisted suicide unthinkable.

HOPE is a single issue group. We recognise that there are many issues that our supporters may be interested in — but we focus solely on euthanasia & assisted suicide. As such we welcome anyone who stands with us on this issue regardless of the positions they hold on any other issue.

HOPE: preventing euthanasia & assisted suicide exists to build a well-informed broadly-based network of groups and individuals to create an effective social and civic barrier to euthanasia and assisted suicide.

Respect for others remains a paramount principle. HOPE will work with anyone who opposes the legalisation of euthanasia and assisted suicide. Political or personal ideology and religious beliefs or practices will be respected. All people who support the principles and practices of HOPE are welcome.

#### Our Objectives:

To oppose the legalisation of euthanasia and assisted suicide and to support measures that will make euthanasia and assisted suicide unthinkable. We will aim to:

• build networks amongst likeminded people across Australia who support our aims;

- present a united voice in presentations to governments or other organisations with respect to issues related to euthanasia and assisted suicide;
- network and exchange information between supporters and concerned people;
- develop an educational and media strategy for educating the public on issues related to euthanasia and assisted suicide;
- build a research team for collecting and assessing information;
- organise events and promote quality speakers who can address issues related to euthanasia, assisted suicide, and hospice/palliative care;
- encourage people from all walks of life to engage in the public debate and to raise such matters with their political representatives;
- create the opportunity for informative debate.

At HOPE we are working for a better informed society – one that understands the real and insurmountable problems with euthanasia and assisted suicide.

At HOPE we are working to help people become involved in building a positive message, in standing up and making a real difference.



# The Honourable Greg Donnelly MLC Rights of the Terminally III Bill 2013

#### **Second Reading Speech**

23<sup>rd</sup> May 2013

Mr President,

I participate in this important debate on the *Rights of the Terminally III Bill 2013*. Honourable members present, past and no doubt future understand that it is a privilege to be given an opportunity to serve the citizens of New South Wales in this place. It is an honour that very few ever get to experience. Since 1824 both men and women have been carrying out the important duties that go with being a member of the Legislative Council. Those duties are many and varied but at the core lies the participation in and overseeing of the making of laws for this state. The ability to do so is derived from the *Constitution Act 1902*. That Act provides for the making of laws for the "peace, welfare and good government of

New South Wales in all cases whatsoever ..."

It is my strong view that the Rights of the Terminally III Bill 2013, being sponsored by the Hon. Cate Faehrmann, not only manifestly fails to meet these key criteria for state laws, it actually seeks to challenge them. Whether the challenge is considered to be express or implied, it seems to me that this is a moot point. I submit that what is being proposed presents unequivocally a clear and present danger to the health, welfare and wellbeing of one of the most vulnerable groups in the state at a time when they overwhelmingly need our care, support and love. I have no doubt in my mind that they would be seriously impacted in a negative way if this bill ever made it onto the statute books. I also believe that a number of members in this House and indeed the other place support this view.

In the time available for me to make contribution on this bill it is not possible to cover every issue deserving of comment associated with the proposed legislation. That being the case, I have decided to limit my reflections to points that deserve particular attention. I place on record that I wish to associate myself with the contributions of the Hon. Walt Secord, the Hon. Marie Ficarra, the Hon. Matthew Mason-Cox, Reverend the Hon. Fred Nile, the Hon. Paul Green and other members who have spoken in opposition to the bill. I wish to associate myself with the public comments of the Hon. Luke Foley, who has articulated concerns and serious shortcomings with the bill. I share those concerns.

In October 2010 I attended the World Federation of Right to Die Societies Biennial Global Conference that was held in Melbourne. As I was not a member of any of the affiliated right to die organisations I could only attend day two of the conference. This day was set aside for participation by members of the general public. The day was organised around the theme "Dying with Dignity—Bridging Principles and Practice". A number of interesting speakers gave presentations on the day. A question-and-answer forum followed the presentations. There were also panel sessions. It was a thought-provoking day and it is simply not possible to consider all the issues that were discussed.

After the event I requested and received copies of a number of the PowerPoint presentations. I must say that the most instructive parts of the day for me were the question-and-answer forums where the presenters were asked to "not pull their punches" and speak frankly. In my assessment, all the speakers took up this invitation. Professor Jan Bernheim from the Department of Human Ecology, Faculty of Medicine, Vrije Universiteit Brussel, who was one of the overseas guest speakers, was very clear in his advice to the Australian euthanasia and physician-assisted suicide advocates present. He strongly encouraged them to adopt the strategy that their colleagues had implemented in Belgium. The strategy, as outlined in his PowerPoint presentation in a nicely prepared flowchart, articulated that euthanasia and physician-assisted suicide had to be drawn into and made part of the medical, nursing, caring, political and general public discourse with respect to palliative care. Wrapping them up in a holistic way with the language palliative care was, using his words, a way of insulating them from criticism and attack.

Another comment, made in a moment of frankness and

worth repeating, was by Professor Margaret Otlowski from the Faculty of Law, the University of Tasmania. For those not aware, that is the same Professor Otlowski who has provided The Greens with ongoing advice about euthanasia and palliative care legislation, not just in Tasmania but also on the mainland. It is the same Professor Otlowski who sent the Hon. Cate Faehrmann what I can best describe as a letter of comfort regarding the bill we are debating today. At the conference Professor Otlowski was asked: Assuming that getting euthanasia legislation into Australian legislatures was a worthwhile and important objective, a position that she openly agreed with, what was, in her view, the best way to "thread the needle"? Without hesitation she said:

"Promote the physician assisted suicide model instead of the strict euthanasia model. In the current context, this is clearly the least path of resistance. I encourage people interested in this matter to look at the legislation operating in Oregon in the US."

I use those examples to help illustrate why I cannot and will not support the bill. I believe that these examples give insight into the motivation of some people supportive of proposed legislation such as this bill. I have no doubt that one of the other participants at the conference, the Hon. Cate Faehrmann, was also paying careful attention to these salient points. I believe that the bill that she has advanced incorporates the thinking outlined by the abovementioned speakers at the conference in Melbourne.

Time is passing and I will have to move through my next points rather quickly. A number of members in this debate have outlined serious technical difficulties associated with the practical operation of this bill. The Hon. David Clarke commented on a number of those difficulties and my parliamentary colleague the Hon. Adam Searle, bringing his legal mind to this debate, identified some key issues involving definitions. I draw the attention of the House to the comments made by the Legislation Review Committee in Legislation Review Digest No. 36/55, pages 15 to 18, which outline, in that

respectful body's point of view, concerns about this bill and its impact on human rights, in particular.

My next point relates to an issue which, in some sense, I believe has not been discussed enough in this debate, palliative care. The bill implies that in New South Wales there is currently readily available to the citizens of this state high-quality palliative care. The fact is that there is high-quality palliative care available to some citizens of this state but unfortunately, and this is not a reflection on the current Minister for Health the Hon. Jillian Skinner, New South Wales has not come up to the mark in relation to funding for palliative care.

I compliment the Hon. Jillian Skinner on her announcement last year of a commitment of an additional \$35 million to palliative care. I saw her in the lift this morning and I said to her that it is a good start but there is a lot more to do. Without hesitation, she agreed that a lot more needs to be done. I believe that she is committed, and she has people working with her and plenty of pests like me who will continue to chase her on this issue as we move the whole issue of

palliative care into the future in New South Wales.

In particular, I thank some people who have worked hard on the issue of palliative care: the immediate past president of Palliative Care NSW, the peak organisation in this State, Peter Cleasby, an outstanding man who has led the debate in New South Wales and who played a facilitative role in getting the current Government to stump up the money last year, the current president, Carolyn Walsh, the executive director, Linda Hansen, who is an outstanding advocate and champion of palliative care, doctors Philip Chye, Maria Ciglione, Frank Brennan and Dr Yvonne McMasters who many of us know from her work in campaigning to get that \$35 million.

In answer to people who wonder why I and others so strongly oppose the proposed legislation, in relation to what we see are fundamental flaws in euthanasia/assisted suicide legislation and our challenging of some of the things that proponents for the legislation claim are not true such as the slippery slope arguments, I draw their attention to a book entitled

Exposing Vulnerable People to Euthanasia and Assisted Suicide, written by Alex Schadenberg. The book has been provided to most members in this House, and probably in the other place as well, as part of the provision of information by the organisation Hope: Preventing Euthanasia and Assisted Suicide, and I thank that organisation for circulating the book.

I conclude by thanking the members who participated in this debate and who I have talked with outside the House, members who agreed with and others who opposed my position. I particularly thank all the people who have sent me emails and I seek their forbearance in my not being able to respond to all of them. We have all received many emails. I appreciate those emails that expressed concerns both favouring and opposing the legislation. I urge members to oppose a proposed amendment of the Hon. Helen Westwood. I urge members to oppose the bill in principle and to defeat it comprehensively.