

**Inquiry into End of Life Choices
Final Report**

**Minority Report by
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EXECUTIVE SUMMARY

The Majority Report does not establish the case for the legalisation of assisted suicide or euthanasia. It is mistaken in asserting that it is possible to fundamentally change medical practice in order to help the small minority of people who experience unendurable pain and that no one will be worse off as a result. The facts say otherwise.

The key arguments that will be developed in this report are that:

- It is possible to respect individual autonomy while not empowering health professionals to actively participate in acts of assisted suicide or euthanasia.
- Even if it can be argued that euthanasia or assisted suicide are justifiable in some instances, the negative consequences arising from legalisation far outweigh the benefits arising in that minority of cases.

This report acknowledges that extremely complex situations can arise at the end of life

Not all pain can be effectively managed, whether it be physical or psychological. In the face of unmanageable pain, some people express a clear desire to end their life. For most of us, witnessing great suffering by another person, particularly a loved one, prompts a strong desire to find a way to end that suffering. That is why many of the people who have a desire and willingness to give assistance to these wishes do so out of compassion and love.

The potential for very difficult situations to arise towards the end of life was reinforced by direct evidence provided to the Committee. This evidence was received in both written form and through testimony. All of the people who gave this evidence exhibited great bravery in telling their stories. This report acknowledges the importance of these peoples' experiences.

It is also important to acknowledge that situations involving unendurable suffering are not limited to the end of life. They can arise as a result of non-terminal diseases, accidents or other changes in circumstances that have ongoing negative consequences on a person's quality of life. Cases occurring near the end of life are generally focussed on in the euthanasia and assisted dying debate since these are widely seen to provide the strongest support for the case for intervention to give effect to a person's wish to die.

It is possible to respect individual autonomy without supporting euthanasia or assisted suicide

For many, the importance of respecting individual autonomy underpins the case for euthanasia and assisted suicide. It is almost universally agreed that adults have a right to make informed choices about their medical treatment, including opting for a withdrawal of treatment. This report supports that proposition.

Euthanasia and assisted suicide are different. They are not simply a matter of whether to give effect to an individual's choice about their own treatment. They necessarily involve third parties, usually medical practitioners, in acts that will intentionally result in death.

As such, acts of euthanasia and assisted suicide move from the private realm into the public realm. Public policy questions such as the risk of unintended consequences and proportionality are relevant and must be considered if regulatory intervention is to be justified.

Euthanasia and assisted suicide are a last resort in only a tiny minority of cases

While not all pain can be managed, it can be managed in the vast majority of cases and the proportion of cases in which pain can be managed is constantly increasing.

Experts in palliative care, oncology and related fields almost unanimously agreed that almost all symptoms arising from physical pain at the end-of-life can now be managed. The palliative care and oncology experts who gave evidence also stated that, over long careers, the number of people expressing a desire to have their life shortened was very small.

Even where there is an expressed desire to die, it is critically important to understand the nuances of such requests. Where the person making the request is experiencing depression or a mental illness, which is relatively common, there are usually other treatment options worth exploring. Holistic palliative care and other forms of assistance can often provide effective relief, even if not complete, and can often lead to a reversal in the expressed desire.

In practice, euthanasia and assisted suicide are a disproportionate response that cause far more social harm than good

The number of instances of euthanasia and assisted suicide is growing rapidly in all major jurisdictions where it is legal. This has been occurring for almost two decades in some jurisdictions, with no sign of abatement. The usage of euthanasia and assisted suicide in practice is far out of proportion to the situations that were originally used to justify the practice in these jurisdictions: namely, that small minority of cases where the symptoms of pain are unmanageable.

Moreover, the rapid growth in documented cases of euthanasia and assisted suicide probably materially understates the actual prevalence of the practice. There is a widespread failure of safeguards and procedures across jurisdictions, including low rates of reporting.

While legalisation was supposed to bring what was occurring in the shadows into the light, legalisation has simply pushed the boundary of what is legal out further and may have increased the amount of activity that occurs beyond the sight of regulators.

In countries with legalised euthanasia or assisted suicide, many vulnerable people are being placed in difficult situations in which they have to make irreversible, complex choices under a great deal of pressure. Evidence suggests that it is doubtful that safeguards are working as intended for such people.

CHAPTER 1 – FRAMING THE ISSUE

This report starts from the premise that adults have a right to control what happens to them. This includes a right to decide which medical treatments are administered to them and a right to have medical treatment fully withdrawn should a person decide that the burden of any treatment would outweigh the likely potential benefits.

A patient should be able to convey a desire to have treatment withdrawn either explicitly while conscious or through a clear statement of their preferences that could take effect should a person fall into an indefinite unconscious state. The importance of this right was reflected in the *Medical Treatment Act 1988* and this report concurs with the right to refuse treatment or have treatment withdrawn as critical.

It is important to stress from the outset that, in cases of both euthanasia and assisted suicide, the ethical dimensions are inherently more complex since third parties are necessarily involved. It is not enough to assert a belief in the individual's right to autonomy. Any system of regulated euthanasia or assisted suicide must involve the active participation of members of the health profession and possibly also other regulatory arms of the state.

In addition to considering how to give effect to the wishes of the patient, the role of medical professionals and the health system more generally in actively bringing about the death of patients must be scrutinised in any discussion of active euthanasia or assisted suicide.

The role of professionals in a regulated euthanasia or assisted suicide regime could take a number of forms, including some or all of the following:

- One or more medical professionals providing approval before an individual is granted access to either euthanasia or assisted suicide.
- One or more medical or related professionals providing counselling before either euthanasia or assisted suicide is administered.
- One or more medical professionals (or a chemist, with approval) prescribing the drug/poison to be used in an assisted suicide.
- One or more medical professionals administering euthanasia.
- Medical professionals or others as deemed appropriate witnessing an assisted suicide.
- Medical professionals and others as deemed appropriate monitoring instances of euthanasia or assisted suicide and possibly hearing appeals at different steps of the regulated process.

Because regulating euthanasia and assisted suicide involves the state regulating how medical professionals can take active steps to bring about death, it is not just a question of individual autonomy.

Euthanasia and assisted suicide involve broader policy questions in relation to how the medical system can best work in the interests of individuals who are either terminally ill or in grave physical

or mental distress. Issues such as unintended consequences and whether procedural breaches can be managed lie at the heart of the issue.

In giving evidence to the House of Lords Select Committee inquiry into the Assisted Dying for the Terminally Ill Bill, Professor Alan Johnson, Emeritus Professor of Surgery at the University of Sheffield observed:

... the impression has been given that obeying patients' wishes is the overriding ethical imperative for doctors. Of course it is important, but it is not paramount. If it were, I would have done many unnecessary operations and some harmful operations in my time as a surgeon (Q 165).¹

He cited, as an example of the need to subordinate individual patient autonomy to the interests of the wider patient community on rare occasions, the refusal of doctors to prescribe antibiotics at a patient's request for relatively trivial conditions because to do so would "produce resistance which might have quite a serious effect on people further down the line".²

The Select Committee concluded that: "We are agreed that patient autonomy cannot be absolute and that there must be some limits set, in the interests of the wider community."³

In the context of euthanasia and assisted suicide, there is arguably a gain from giving effect to some patients' wishes to hasten their death. But this must be weighed against the potential for societal harm through a range of potential negative consequences, including: vulnerable people being pressured into euthanasia or assisted suicide; people having their death hastened without having given proper consent; and a gradual broadening of practices without transparent public consideration. As will be shown below, evidence from jurisdictions that have legalised euthanasia and assisted suicide shows that all of these are real risks.

The House of Lords Select Committee supported this framing of the issue:

... we cannot address the issue of personal autonomy in isolation and ... we must proceed to look at some of the 'real world' issues which have been raised and to try to assess the balance between greater personal choice for some people and increased potential harm for others ...⁴

What is the real choice that we face? It is important to acknowledge that neither current regulatory arrangements nor a world with legalised euthanasia/assisted suicide will be free from unendurable suffering. We are ultimately choosing between two systems in which some suffering will be difficult to treat or manage and in which regulation is difficult to perfectly enforce.

The Majority Report gave considerable weight to the evidence from the Coroners Court of Victoria. This evidence included details of a number of confronting situations in which people committed suicide, often in very distressing ways, in order to end suffering. What the Majority Report doesn't

¹ House of Lords, *Assisted Dying for the Terminally Ill Bill – First Report*, Select Committee on Assisted Dying for the Terminally Ill Bill, Session 2004-05, 3 March 2005, paragraph 45.

² *Ibid*, paragraph 45.

³ *Ibid*, paragraph 62.

⁴ *Ibid*, paragraph 63.

make clear is that many of the instances raised by the Coroners Court wouldn't fall within the scope of its proposed regime. This highlights the difficult choice that we face in practice.

As Table 1 outlines, we do not face a choice between respecting autonomy and bringing dubious actions out of the shadows on the one hand versus an intransigent, knee-jerk protection of the status quo on the other. Rather, we face a choice between two imperfect situations. In neither will the wishes of all people to die be fully complied with. In neither will there be full and transparent compliance with the law.

Rather, the choice as to whether to reform or not should be guided by an informed judgement of the likely consequences for our overall treatment of people in vulnerable situations.

Table 1: Characteristics of current arrangements vs legalised euthanasia/assisted suicide

Current arrangements	Legalised euthanasia or assisted suicide
<p>Harrowing deaths exist - although in the vast majority of cases, physical pain can be managed effectively with modern pain relief and palliative care. These instances are a small and shrinking minority of overall deaths.</p>	<p>Harrowing deaths will still exist – although there will probably be less in the category of deaths explicitly allowed under the euthanasia/assisted dying regime. The degree to which there are less deaths involving unmanageable physical or psychological pain will depend upon the permissiveness of the scheme.</p>
<p>Psychological pain that is difficult to treat exists – although treatment in this sphere is improving.</p>	<p>Psychological pain that is difficult to treat will continue to exist – unless a very permissive regime is introduced, such as in Belgium. Under such a permissive regime, the effectiveness of safeguards will be extremely difficult to ensure.</p>
	<p>The number of instances of euthanasia or assisted suicide will probably rise rapidly and this increase is likely to persist. In foreign jurisdictions with legalised euthanasia or assisted suicide, there has been a rapid and sustained growth in the number of deaths and in no jurisdiction is there evidence that this increase will slow down.</p>
	<p>It is likely that the enforcement of safeguards will be difficult. In jurisdictions with legalised euthanasia or assisted suicide, there is systemic non-compliance with the law. This includes:</p> <ul style="list-style-type: none"> • non-reporting of many instances of euthanasia/assisted suicide; • incomplete awareness by regulators of breaches of the law; and • incomplete enforcement by health regulators and law enforcement of breaches.
<p>The law is currently not fully enforced. This can take a number of forms, including: prosecutorial discretion and sentencing leniency, particularly in relation to cases where people are killed or assisted in their suicide by loved ones.</p>	<p>It is unclear if enforcement of the law will improve at all. In jurisdictions with euthanasia and assisted suicide, it is acknowledged by regulators that considerable activity occurs at the edges of the law and that they are powerless to monitor, let alone prevent, much of this activity.</p>

CHAPTER 2 – ALMOST ALL CASES OF PAIN ARE CURRENTLY MANAGEABLE

In almost all cases where a patient experiences a great deal of pain, including terminal cases, the symptoms of that pain can be managed by current best practice in pain relief and palliative care. It is important to note that the capacity of health practitioners to manage the symptoms of pain is increasing over time.

2.1 Pain relief is effective in almost all cases

A number of expert practitioners in palliative care gave evidence to the Committee in relation to the frequency of cases in which it was possible to manage pain at the end of a patient's life. While it is not possible to put a precise percentage on this proportion, the experts were unanimous in their assessment that it was rare that pain couldn't be managed.

This included the following evidence:

Associate Professor Daryl Jones, Austin Health: "... in 20 years as a clinical practitioner, the number of patients I have seen who die to whom that applies is the overwhelming minority."⁵

Associate Professor Peter Hunter, Alfred Health: "We do know that in almost all patients, if we do a proper assessment and understand that the drugs are available, we can alleviate pain and we can do a good job of that."

"I have never not been able to control anyone's symptoms around pain once you have got them on the right treatment path, be it narcotic analgesia or infusion pumps et cetera, so I think that if anyone dies in pain, that is an absolute travesty because there is capacity to really manage that effectively in this day and age."⁶

Moreover, the proportion of patients for whom pain is manageable is rising. When asked if palliative care techniques had improved, Dr Michelle Gold, Director of the Palliative Care Unit at the Alfred Hospital stated that:

Dr Michelle Gold: There are always new medications available in that sense. We are having increasingly fruitful interactions with some of our interventional colleagues to provide pain relief with various procedures and interventions that are sometimes much better directed than the medications are and hopefully have fewer side effects. It is terrific that there are new techniques – new ways of delivering some of the old medication.⁷

⁵ Associate Professor Daryl Jones, *Transcript of evidence*, 5 August 2015, p24.

⁶ Associate Professor Peter Hunter, Geriatrician and Director of Aged Care, Alfred Health, *Transcript of evidence*, 15 October 2015, p55.

⁷ Dr Michelle Gold, Director of the Palliative Care Unit of the Alfred Hospital, *Transcript of evidence*, 23 July 2015, pp56-57.

2.2 Knowledge about pain relief options can provide considerable comfort

Many health practitioners who provided evidence to the Committee spoke of the considerable potential to provide patients with peace of mind by clearly communicating the pain relief options available to them. For example Ms Deidre Bidmade, Vice-President of the Warrnambool and District Community Hospice, stated that:

Ms Deidre Bidmade: ... in the last 10 years the biggest factor when somebody is dying is how I am going to die. Is my pain going to be out of control? These conversations before somebody is in their last phase of dying is so important, because if you allay those fears and reassess the fact that we have such wonderful drugs out there to ensure that people are not in pain and that we do have things like Niki syringe drivers, so that you can go home with that in situ and that can be titrated to the needs every day, if you can give people peace of mind that they are supported in the journey and that there is no need for acceleration of symptom, that in my experience has been most of the underlying issue.⁸

This view was supported by Associate Professor William Silvester, President of the International Society of Advance Care Planning and End of Life Care:

Associate Professor William Silvester: I am amazed by the number of times that I have gone to walk away and some has called me back and said, 'Look doctor, I didn't tell you, but in fact I've been thinking about euthanasia, and now that you've been able to lift such a weight off my shoulders and I can now be sure and confident that I am going to get the care that I want at the end in the way that I want it, I can now concentrate on living as well as possible. I don't have to think any longer about getting Nembutal or saving up all of my prescription tablets or whatever so that I can do something before I lose control, because now I can see that even when I reach a point where I no longer have control, I will still get what I want and I will not get what I do not want.'⁹

2.3 Very few people ask to be killed – especially if they are aware of care options

Dr Ranjana Srivastava recently wrote an internationally acclaimed book, "Tell me the truth" dealing with the meaning of a good life and good death and the ethics of end-of-life interactions. She is an oncologist with considerable experience and adjunct associate professor in the Monash University Faculty of Medicine, Nursing and Health Sciences. Dr Srivastava gave evidence to the Committee in relation to the issue of how often people seek active intervention by a doctor to end their life:

Dr Srivastava: ... from 15 years of experience ... the most informed I can tell you is that in all my career there have been no more than two or three people at most, in the thousands of patients I have seen, who have said, 'I have had enough. I want to die.'¹⁰

⁸ Ms Deidre Bidmade, Vice-President of the Warrnambool and District Community Hospice, *Transcript of evidence*, 30 July 2015, p27.

⁹ Associate Professor William Silvester, President of the International Society of Advance Care Planning and End of Life Care, *Transcript of evidence*, 23 July 2015, pp63-64.

¹⁰ Dr Ranjan Srivastava, Adjunct Associate Professor, Faculty of Medicine, Nursing and Health Sciences, Monash University and Oncologist, *Transcript of evidence*, 19 August 2015, p20.

This was corroborated by other evidence, including from Professor Peter Hudson, Director of Palliative Care at St Vincent's Hospital:

Professor Peter Hudson: We have been collecting data in two large teaching hospitals for about 15 years now, and it shows that less than 1 per cent of patients referred to the palliative care consultation service actually request euthanasia.¹¹

Even where people ask to die or ask to be killed, the subtle nuances in what they are communicating can only be interpreted by an expert:

Dr Natasha Michael: One of the questions I am always asked is: do patients ask you to kill them? The answer is: yes. I do not use the term 'request for euthanasia'; I use the term, 'They express a desire for death'. Many might have heard me use this terminology or expression before.

People say one of three things to me: 'I want to die', 'Let me die' or 'Kill me'. The people who are saying 'I want to die' are people who are saying: my suffering is so unbearable at this point in time, with my pain, my distress or the burden I am placing on my family, death has to be a better option. The answer to that is not injecting them with a drug or providing barbiturates; the answer to that is saying, 'How can I help you with these factors that are making you feel that death has to be the better option?' The 'Let me die's' are saying, 'You know what, I have fought this fight. I have run the course. I am 85 — or I am 63 — I have had six lines of chemotherapy. I have had enough. Let me die'. **The 'Kill me' is from a really, really small minority** [emphasis added]. Most health professionals are not trained to unpick these things. They lump them together in a singular cohort, so you think of the danger you pose when people come to you and express a desire for death when actually what they are saying is, 'My suffering is so unbearable that I just want you to help me'. The risk is phenomenal.¹²

If you have an unskilled practitioner, you do not have the ability to distinguish these complex psychosocial phenomena. The risk is too high ... I have seen too many people express a desire for death when actually all they are asking for is help.¹³

To set up a system in which many GPs face a situation in which they have to interpret complex end-of-life situations will create significant risks particularly given that most GPs do not have training in this specific area of care and will face such situations rarely. As will be outlined below in detail, these risks are further compounded by the inadequacy of safeguards in practice.

¹¹ Professor Peter Hudson, Director, Centre for Palliative Care, St Vincent's Hospital, *Transcript of evidence*, 24 February 2016, p4.

¹² Dr Natasha Michael, Director, Palliative Care, Cabrini Health, *Transcript of evidence*, 16 September 2015, p9.

¹³ Dr Natasha Michael, Director, Palliative Care, Cabrini Health, *Transcript of evidence*, 16 September 2015, p10.

2.4 Conclusion: A very small number of cases are problematic under current arrangements

For the vast majority of people, modern pain relief and palliative care can manage physical pain right up to the end of life. If euthanasia or assisted suicide was legalised so as to deal with this type of situation, one would expect to see a small and relatively stable number of cases over time. As will be outlined in the following chapter, the evidence differs markedly from this in every major jurisdiction that has legalised euthanasia or assisted suicide.

Psychological pain is sometimes more difficult to manage. However, once psychological pain is used as a rationale for euthanasia or assisted suicide, difficulties arise as this type of pain is not particularly associated with end-of-life issues. It can therefore be used to justify the extension of euthanasia and assisted suicide regimes to non-terminal situations. Moreover, as will be argued in Chapter 4, allowing euthanasia or assisted suicide in cases involving profound psychological pain is problematic as the patient's condition will likely impact on their capacity to provide consent.

CHAPTER 3 – THE FREQUENCY OF EUTHANASIA AND ASSISTED DYING IS RISING RAPIDLY

3.1 In all jurisdictions where euthanasia or assisted suicide is legal, there has been a sharp, sustained upward trend in the number of deaths – often over long periods of time

In all major jurisdictions where euthanasia or assisted suicide is legal, the number of cases has increased sharply ever since legalisation. This increase has been rapid and sustained. In no major jurisdiction is a plateau in numbers evident.

The majority of this increase is not due to the aging of society or to a growing awareness of end-of-life options. As will be outlined in Chapter 4, it is most likely to be due to factors such as:

- An expansion in the categories of people eligible to opt for euthanasia or assisted dying either through formal legislative change or, sometimes less transparently, gradual changes in the interpretation and application of existing provisions.
- A “normalisation” of euthanasia or assisted dying in the medical system and across the broader culture.
- Systemic failures in safeguards.

The Majority Report sidesteps this issue. It provides no attempt to explain either why such persistent growth in cases is occurring or whether the risks associated with this trend can be managed.

3.2 A summary of empirical trends in the number of cases of euthanasia and assisted suicide across major jurisdictions

Over the next two pages, the number of cases of euthanasia and assisted suicide in the major jurisdictions that have legalised either procedure are set out.

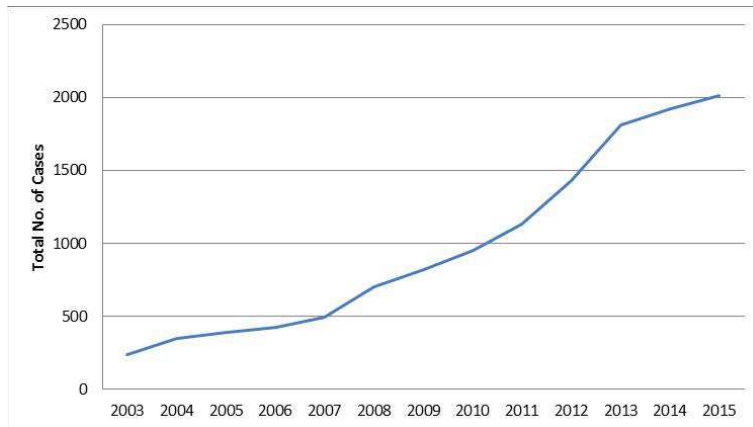
The data from which the graphs and associated growth rates were derived was all obtained from public sources.

The period of data availability varies by jurisdiction, but in three instances, data is available for more than 10 years and in two jurisdictions for more than 15 years.

EUROPEAN JURISDICTIONS

Figures 1 to 3 contain the trend in the total number of cases of euthanasia and assisted dying in Belgium, the Netherlands and Switzerland over the period for which reliable data is available. Data is available for 12 years in the case of Belgium, 7 years in the case of Netherlands and 16 years in the case of Switzerland.

Figure 1: Belgium



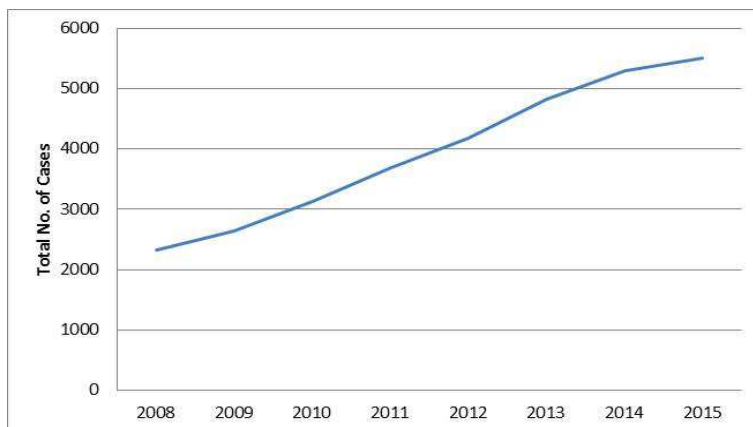
Total Growth 2003-2015:

235 → 2,012

Compound annual growth rate:

19.6%

Figure 2: Netherlands



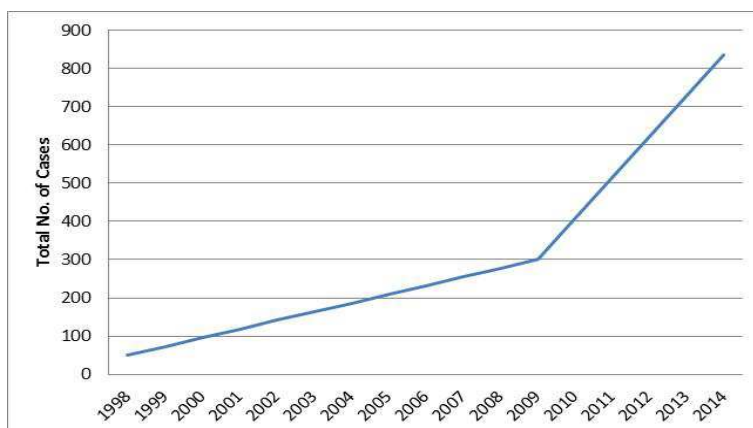
Total Growth 2008-2015:

2,331 → 5,516

Compound annual growth rate:

13.1%

Figure 3: Switzerland



Total Growth 1998-2014:

50 → 836

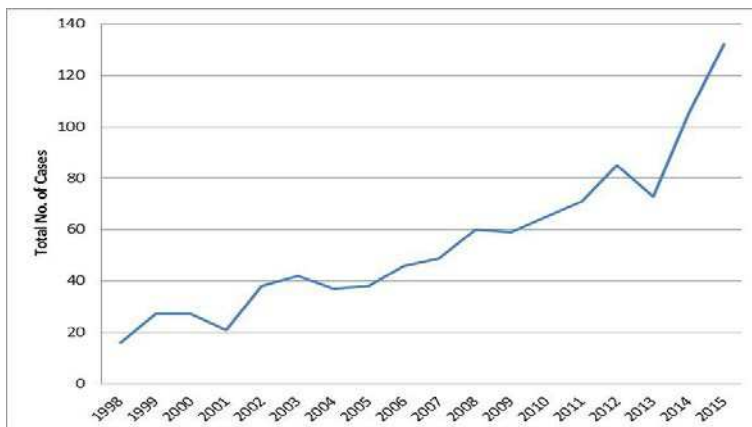
Compound annual growth rate:

19.2%

NORTH AMERICAN JURISDICTIONS

Figures 4 and 5 contain the trend in the total number of cases of euthanasia and assisted dying in Oregon and Washington State over the period for which reliable data is available. The data is available for 17 years in the case of Oregon and 5 years in the case of Washington State.

Figure 4: Oregon



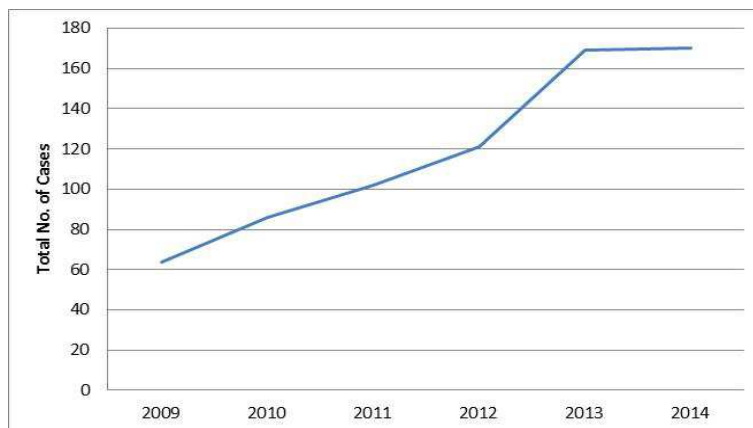
Total Growth 1998-2015:

16 → 132

Compound annual growth rate:

13.2%

Figure 5: Washington State



Total Growth 2009-2014:

64 → 170

Compound annual growth rate:

21.6%

For Belgium, the data was compiled from the official statistics of the Federal Control and Evaluation Commission. These are reported to the Belgian legislature.¹⁴

For the Netherlands, the data is sourced from the Dutch Regional Euthanasia Review Committees.¹⁵

¹⁴ <http://www.lesoir.be/637943/article/actualite/belgique/2014-08-27/euthanasies-ont-augmente-55-en-deux-ans-infographie-for-years-2002-2013>.

For 2014 and 2015, see <http://www.news24.com/World/News/belgian-euthanasia-cases-hit-record-high-20160127> which cites official government statistics.

¹⁵ The Netherlands has five regional euthanasia review committees. The review committees assess whether a doctor who has performed or assisted suicide, euthanasia, has complied with the due care criteria set out in the *Termination of Life on Request and Assisted Suicide (Review Procedures) Act*. An annual report is issued each year by the Dutch Regional Euthanasia Review Committees.

The statistics for Switzerland are derived from a number of sources. Swiss authorities published the first official statistics on assisted suicide in March 2012. According to the Federal Statistical Office, the number of Swiss residents who died from assisted suicide has increased continuously between 1998 and 2009. The Federal Statistical Office reported that, in 2009, approximately 300 assisted suicide deaths occurred (4.8 per 1000 deaths or 0.48% of all deaths) compared with fewer than 50 deaths in 1998.¹⁶ In 2014, the total number of assisted suicide deaths in Switzerland, including deaths at Dignitas and the Eternal Spirit clinic, was around 836.¹⁷

Given the lack of data, Figure 3 is derived by linear interpolation between the data points provided by the Federal Statistical Office for 1998 (using 50 to be conservative in relation to growth rates) and around 300 in 2009.¹⁸ There is a further linear interpolation between the 2009 figure and 836 in 2014.

Recent media articles detailing the number of deaths at individual organisations corroborate this overall trend. It has been reported that the Swiss assisted suicide organisation (EXIT) helped 782 people end their lives in 2015, 199 more than the previous year (583 in 2014).¹⁹ For 2011, it has been independently reported that the right-to-die organisation EXIT assisted 416 deaths, up from approximately 348 deaths in 2010.

In Switzerland, a material number of deaths are from non-residents. The 2011 figure for non-resident deaths reported by the organisation Dignitas was 149.²⁰ *The Atlantic* reported that, in the decade leading up to 2010, over 1,000 people had received assisted suicide at Dignitas.²¹

The data for Oregon and Washington State is sourced from the relevant State Department of Health reports.²²

Source: Dutch Regional Euthanasia Review Committees, Annual Reports, 2012-2015.

¹⁶ Switzerland, Federal Statistical Office (FSO), [Cause of death statistics: Assisted suicide and suicide in Switzerland](#), accessed 11 May 2016.

¹⁷ A Schadenberg, [Switzerland assisted suicides jump 34% in 2015](#), Euthanasia Prevention Coalition, web blog, 3 March 2016.

See, <http://alexschadenberg.blogspot.com.au/2016/03/switzerland-34-increase-in-assisted.html> (Accessed 30 May 2016)

¹⁸ Shariff, M.J., "Assisted death and the slippery slope – finding clarity amid advocacy, convergence, and complexity", *Current Oncology*, 2012, Jun; 19(3): 143-154, <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3364764/> (Accessed 30 May 2016)

¹⁹ [EXIT reports jump in assisted suicide numbers](#), Swissinfo.ch, website, 2 March 2016. (Accessed 30 May 2016)

²⁰ Shariff, M.J., "Assisted death and the slippery slope – finding clarity amid advocacy, convergence, and complexity", *Current Oncology*, 2012, Jun; 19(3): 143-154, <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3364764/> (Accessed 30 May 2016)

²¹ http://www.theatlantic.com/magazine/archive/2010/03/death-becomes-him/307916/?single_page=true, March 2010, Vol. 305, Issue 2, p68.

²² Oregon State Health Authority, Death With Dignity Act, Annual Report 2014. See <http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year18.pdf> for the most recent report.

See also: Washington State Department of Health, Death with Dignity Act Report, 2014. <http://www.doh.wa.gov/YouandYourFamily/IllnessandDisease/DeathwithDignityAct/DeathwithDignityData>

3.3 The sustained and long-term nature of growth

In all jurisdictions, the increase in the total number of cases has been sharp and sustained. In no jurisdiction is there clear evidence that growth rates are plateauing.

The total number of deaths is higher in the European jurisdictions than the North American jurisdictions, which is to be expected given that the former are more permissive.

To put the current number of deaths in context, in the Dutch speaking part of Flanders, physician-assisted deaths constituted 3.8% of deaths in 2007 and 6.3% of deaths (or 1 in 16) in 2013.²³

A rate of over 6% of all deaths being carried out via physician-assisted deaths - and still rising - can be considered as nothing other than a major shift in practice and culture, particularly given that euthanasia was originally justified in Belgium as a last resort for the tiny minority of people for which palliation could not provide adequate care.

Table 2: Annual growth rate in cases of euthanasia and assisted suicide in selected jurisdictions

Country	% Annual Growth in Total Deaths	CAGR ²⁴ in euthanasia / assisted suicide	No. of years over which CAGR calculated
UNITED STATES	0.5 ²⁵		
Oregon		13.2 ²⁶	17
Washington		21.6 ²⁷	6
EUROPE			
Belgium	0.3 ²⁸	19.6 ²⁹	12
The Netherlands	-0.3 ³⁰	13.1 ³¹	7
Switzerland	0.3 ³²	19.2 ³³	16
AUSTRALIA			
Victoria	1.6 ³⁴		

²³ Lemmens, Trudo, The Conflict Between Open-ended Access to Physician-Assisted Dying and The Protection of the Vulnerable: Lessons from Belgium's Euthanasia Regime in the Post-Carter Era, (forthcoming), Catherine Regis, Lara Khoury & Robert Kouri, eds., *Key Conflicts in Health Law*, (Cowensville: Yvon Blais, 2016), pp30-31.

²⁴ Compound annual growth rate

²⁵ <http://stats.oecd.org/> - CAGR from 2000-2013

²⁶ Compound annual growth rate: 1998-2015

²⁷ Compound annual growth rate: 2009-2015

²⁸ <http://stats.oecd.org/> - CAGR from 2000-2013

²⁹ Compound annual growth rate: 2003-2015

³⁰ <http://stats.oecd.org/> - CAGR from 2000-2010 (latest data point)

³¹ Compound annual growth rate: 2008-2015

³² <http://stats.oecd.org/> - CAGR from 2000-2103

³³ Compound annual growth rate: 1998-2015

³⁴ ABS 3302.0, <http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/3302.02014?OpenDocument>, 2004-2014 (Accessed 30 May 2016)

Annual growth rates in the order of 13 – 20 per cent are extremely high. It is worth noting that the impact of cumulative growth rates of this magnitude over the medium term can be deceptive. What appears to be manageable at first can rapidly lead to very large numbers and, in the case of euthanasia and assisted suicide, a very high proportion of overall deaths.

For example, the total number of cases in Belgium has increased by 756% over 12 years and the number of cases in Oregon is 725% higher over the 17 years following legalisation.

Table 3 indicates what would happen in jurisdictions with legalised euthanasia and assisted suicide if currently observed growth rates continue. The final two columns indicate how many multiples of the base year frequency would occur after 10 and 20 years of sustained growth. These are not long periods of time.

For example, if Oregon’s observed annual growth rates were applied to a base number of 100 deaths, that number would grow to 350 after 10 years and 1,200 after 20 years. Higher growth rates, such as observed in Washington State, Belgium and Switzerland result in even more dramatic growth. Based on growth rates observed in Washington State, a base number of 100 cases in year 1 would grow to 700 ten years after commencement and 5,000 after 20 years.

It is not at all clear what kind of growth to expect in jurisdictions with legalised euthanasia and assisted suicide over the upcoming 10 or 20 years. However, we cannot rule out continued growth in the order of what we have already observed in jurisdictions such as Oregon and Switzerland.

Table 3: Annual growth rate in the cases of euthanasia and assisted suicide in selected jurisdictions

Country	Observed annual growth rate by jurisdiction	Cumulative growth over 10 year period	Cumulative growth over 20 year period
UNITED STATES			
Oregon	13.2% ³⁵	3.5x	12x
Washington	21.6% ³⁶	7x	50x
EUROPE			
Belgium	19.6% ³⁷	6x	35x
The Netherlands	13.1% ³⁸	3.4x	12x
Switzerland	17.6% ³⁹	5.8x	34x

It is difficult to say, based on available data, why this is happening. Many jurisdictions with legalised euthanasia and assisted suicide do not provide for transparent reporting in relation to case details. The following chapter will outline five possible reasons for the rapid, sustained growth in the number of observed cases.

³⁵ Compound annual growth rate: 1998-2015

³⁶ Compound annual growth rate: 2009-2015

³⁷ Compound annual growth rate: 2003-2015

³⁸ Compound annual growth rate: 2008-2015

³⁹ Compound annual growth rate: 1998-2015

CHAPTER 4 – REASONS FOR THE GROWING PREVALENCE OF EUTHANASIA AND ASSISTED DYING

There are many possible reasons why the number of cases of euthanasia and assisted suicide is rising so quickly and over such a long period of time. Understanding the causes of this growth is critical if we are to be confident that public policy objectives can be achieved through legalisation.

There is considerable evidence that this rapid and sustained rise in numbers is attributable in part to a growth in the scope of the practice, to a normalisation of the practices and to a failure of safeguards.

Box 1: Key public policy considerations

The Victorian Parliament should carefully evaluate evidence which demonstrates that:

- In jurisdictions where it is legal, access to euthanasia and assisted suicide is not being limited to those people experiencing unendurable physical pain, even where this was the original rationale for legalisation.
- Over time, the rapidly growing number of cases of euthanasia and assisted suicide reflects a disturbing normalisation of the practice, even though the original rationale for legalisation usually stressed that it was only intended to be used as a last resort in exceptional cases.
- Safeguards are systemically and routinely failing across a number of jurisdictions. Many of these safeguards are relied upon in the Majority Report without evidence that they will work in practice.

4.1 A greater awareness of rights unlikely to be a sustained driver of growth

Greater awareness of access to euthanasia or assisted dying could possibly have driven a growth in total cases in the months and even years following introduction of each scheme. As can be seen in Figures 1 to 5 however, high growth rates in total numbers have not abated in any jurisdiction, even where data exists for periods of almost two decades. In no jurisdiction is there any indication that growth rates are slowing. This suggests that sustained growth is due to factors other than community awareness.

4.2 An aging demographic contributes only a small share of overall growth

An aging demographic is often put forward as a possible reason why the number of cases is rising.

Aging is not a major factor driving the growth in the number of cases of euthanasia or assisted dying in any of the jurisdictions for which data is available. As Table 2 shows, the total number of deaths over the period 2000-2010 grew at less than 1 per cent per annum in all relevant jurisdictions – and indeed it fell in the Netherlands. The change in the total number of deaths is less than one tenth of the total change in euthanasia and assisted dying cases.

4.3 Scope creep is occurring in at least some jurisdictions

There is a long-standing debate in ethics and jurisprudence as to the nature of the ethical difference (if there is one) between an act and an omission that lead to the same outcome. In the context of medical care, the debate centres on whether there is an ethical difference between a decision to end or withdraw treatment by a health practitioner and that same health practitioner actively taking part in ending someone's life.

Regardless as to one's views on whether there is a meaningful ethical difference between these two situations, the distinction between withdrawing treatment and undertaking a positive action is clearly defined. The logical and philosophical arguments on either side of debate are well developed and have been clearly articulated over centuries.

What is much less clear is the ethical difference between various types of action. For example, if one accepts that euthanasia or assisted suicide can be ethical in some situations, that raises subsequent questions such as whether it should be available only for people with a terminal condition or also for those suffering from a condition that is "unbearable", albeit not terminal. Is physical pain necessary to trigger justifiable action or is psychological pain also sufficient? Is explicit consent required? If euthanasia or assisted suicide is justified only for people suffering from a terminal condition, what does "terminal" mean? Must death be expected within 3 months, 6 months, a year? Should an age limit be placed on consent? And so on.

The reason why the "slippery slope" argument has credibility in this context is that, once euthanasia or assisted suicide is accepted for a limited subset of situations, there is very little by way of logical or philosophical argument to stop the expansion of categories.

- If euthanasia or assisted suicide is permitted for those with a terminal condition in order to alleviate suffering – why not alleviate suffering of the same magnitude in those whose condition is not terminal?
- If consent is critical – then why limit availability to adults if "mature minors" can also give meaningful consent in other contexts such as joining the military.
- If advanced care directives can be used to justify the cessation of invasive and possibly painful medical procedures, why should advanced care directives not also be used to justify active euthanasia?

This is why the limitations included in euthanasia and assisted suicide regimes often come under immediate pressure as soon as these schemes are enacted. This takes two main forms. The first is attempts to explicitly expand the categories of situations in which euthanasia or assisted suicide is legal. The second is to reinterpret existing categories more broadly. As will be outlined below, reinterpretation has been undertaken in practice by both non-legislative and non-judicial bodies.

Often, legislation is passed with limitations that are designed to secure its passage through parliament. Where this "pragmatic" approach is adopted, these limits will almost inevitably be tested once the regime is in place.⁴⁰

⁴⁰ It is widely accepted that in Belgium, at least some of the restrictions contained in the initial legislation were included so as to secure passage of the Bill. Lemmens, Trudo, *The Conflict Between Open-ended Access to Physician-Assisted Dying and The Protection of the*

Some would argue that a slippery slope argument is flawed in that it doesn't acknowledge that subsequent changes might be justified on the basis of sound reasoning and policy formulation. That is true. There isn't anything wrong, per se, with legislation that has the potential to change.

The slippery slope argument is less concerned with the merits of each future potential change, and more with the inherent "momentum" in the system. The argument is that, once legalised, there will be a tendency for euthanasia and assisted suicide schemes to expand in scope since the logical and philosophical boundaries between different types of pro-active hastening of death are far weaker than the boundary between omissions and actions.

As will be argued below, the evidence bears this out in a number of jurisdictions.

4.3.1 Scope creep through legislative expansion of categories

Legislative changes have either been implemented or are under active consideration in a number of jurisdictions:

Belgium: euthanasia for children. The original euthanasia legislation in Belgium restricted access to people over the age of 18 years of age. On one reading, children were specifically excluded from the ambit of the legislation as "it was deemed so controversial that including it would have threatened approval of the Euthanasia Bill."⁴¹ In 2014, an amendment was passed that allowed for euthanasia by "mature minors".

Belgium: other changes under consideration by the legislature. In Belgium, a series of other legislative expansions of the euthanasia regime have been submitted to parliament, including:

- Requiring doctors to make referrals, even if it is against their conscience
- Permitting euthanasia for dementia patients
- The use of advanced care directives for people in an unconscious state⁴²

Canada: physician assisted dying for minors. While the *Carter* judgement by the Canadian Supreme Court only applied to competent adult persons, the Provincial-Territorial Advisory Group (PTAG) has already recommended allowing physician assisted dying for minors. Recommendation 17 of the PTAG Final Report is that:

Access to physician-assisted dying should not be impeded by the imposition of arbitrary age limits. Provinces and territories should recommend that the federal government make it clear in its changes to the Criminal Code that eligibility for physician-assisted dying is to be based on competence rather than age.⁴³

Vulnerable: Lessons from Belgium's Euthanasia Regime in the Post--Carter Era, (forthcoming), Catherine Regis, Lara Khoury & Robert Kouri, eds., *Key Conflicts in Health Law*, (Cowensville: Yvon Blais, 2016), p28.

⁴¹ Lemmens, Trudo, The Conflict Between Open-ended Access to Physician-Assisted Dying and The Protection of the Vulnerable: Lessons from Belgium's Euthanasia Regime in the Post--Carter Era, (forthcoming), Catherine Regis, Lara Khoury & Robert Kouri, eds., *Key Conflicts in Health Law*, (Cowensville: Yvon Blais, 2016), p27 citing Griffiths, John, Heleen Weyers and Maurice Adams, *Euthanasia Law in Europe*, Portland, Hart Publishers, 2008, p328.

⁴² European Institute of Bioethics, *Euthanasia in Belgium: 10 years on*, 2012, p4.

⁴³ Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying, *Final Report*, November 30 2015, Recommendation 17, p34. See: http://www.health.gov.on.ca/en/news/bulletin/2015/docs/eagreport_20151214_en.pdf

4.3.2 *Non-legislative and informal extensions within an existing framework*

Physician-assisted dying in Belgium is an example of informal slippage in the scope of the law. In his expert review for the Canadian Attorney-General, Professor Montero found that:

The Belgian legislator clearly intended to exclude physician-assisted suicide from the scope of the Act on euthanasia. This intention was criticized and debated extensively when the Act was being developed. A number of amendments were introduced to incorporate physician-assisted suicide into the scope of the Act, but they were all rejected to the Conseil d'Etat's astonishment.

After the Act was passed, parliamentarians deemed it necessary to propose bills to amend the Act on euthanasia to include physician-assisted suicide performed under the same conditions as those applicable to euthanasia. To them, it is clear that physician-assisted suicide is not covered by the Act and therefore constitutes an illegal practice within the meaning of the Act as it is currently written.

Therefore, it is surprising that the Commission de controle regularly approves reported physician-assisted suicide cases and has been doing so since its first official report, stating that the practice "falls within the scope of the Act, as it is currently written ..."⁴⁴

Lemmens argues that, in Belgium:

... the vague and open-ended nature of the terms 'medically hopeless situation' as well as a very subjective interpretation of the term 'constant and unbearable physical or mental suffering' have clearly opened the door to many instances of euthanasia that are controversial if not outright problematic.⁴⁵

The Netherlands Organisation for Health Research and Development (ZonMw) published the second evaluation report on the functioning of the *Termination of Life on Request and Assisted Suicide (Review Procedures) Act* in 2012. The report finds that a more liberal approach is emerging in relation to requests from patients from some groups, such as those with mental illness or dementia.

This shift can be seen in medical opinion as well as in the policy position of the regional euthanasia review committees. The evaluation report states that:

... this development does not imply an expansion of the legal requirements: it should be seen as further conceptualisation of the meaning and scope of the requirements, that are formulated rather "openly" in the Act.⁴⁶

⁴⁴ Montero, Professor Etienne, Affidavit to *Lee Carter v The Attorney General of Canada et al*, Supreme Court of Canada, No. 35591, pp52-53.

⁴⁵ Lemmens, Trudo, *The Conflict Between Open-ended Access to Physician-Assisted Dying and The Protection of the Vulnerable: Lessons from Belgium's Euthanasia Regime in the Post-Carter Era*, (forthcoming), Catherine Regis, Lara Khoury & Robert Kouri, eds., *Key Conflicts in Health Law*, (Cowensville: Yvon Blais, 2016), p36.

⁴⁶ Regional Euthanasia Review Committees, *Annual Report 2012*, p3.

As is noted below, the number of instances of people with dementia and mental illness being euthanised in the Netherlands is rising rapidly. This could reflect regulatory creep.

On 7 January 2016, the *Netherlands Times* report that:

The Ministries of Public Health and Security and Justice updated their “guide” on euthanasia to give people suffering from severe dementia the option of euthanasia, even if they are unable to express the wish themselves. This is only possible if the patient wrote a declaration with his wish for euthanasia while he was still clearheaded, broadcaster NOS reports.⁴⁷

The proposed physician-assisted dying regime in the Majority Report will establish an entity responsible for monitoring assisted dying within Victoria. Given the experiences of such entities in other jurisdictions, the risk that a supervisory body in Victoria will unilaterally extend the scope of any assisted dying regime through non-transparent interpretation of legislative provisions is a real risk and of great concern.

⁴⁷ <http://www.nltimes.nl/2016/01/07/euthanasia-okd-for-dementia-patients-who-request-it-when-lucid/> (Accessed 30 May 2016)

4.4 There is evidence of a “normalisation” of euthanasia and assisted suicide

Chapter 3 presents clear evidence of an upward and persistent trend in the number of cases of euthanasia and assisted suicide following legalisation. This section will refer to commentary that relates to a contemporaneous normalisation of the practice.

The term “normalisation” in this context is used to indicate that, once legalised, euthanasia and assisted suicide are increasingly taken for granted and seen to be unexceptional both within the medical profession and more broadly within society.

This is important given that the original rationale for euthanasia and assisted suicide in most jurisdictions, and in the Majority Report, is to deal with a set of circumstances that is extremely rare.

4.4.1 Belgium

Belgium currently has one of the most liberal euthanasia regimes in the world. Carine Brochier of the European Institute of Bioethics reported that one physician had told her:

You are right to say that many euthanasia cases are not [officially] declared. I myself have practiced euthanasia very many times, and I never declared them. It is too personal and a matter between the patient and his doctor. No need to publicise it.⁴⁸

The open-ended regime in Belgium evokes “a culture of normalization of active life-ending interventions by physicians that may have long-term consequences which are hard to predict.”⁴⁹

In Belgium, the number of cases of euthanasia is rising rapidly. One would think that this would mean that a growing number of instances of euthanasia applications are falling into more difficult categories. But a recently published survey of physicians in Flanders found a rise in the proportion of requests granted from 56.3% in 2007 to 76.8% in 2013.⁵⁰ This could indicate a growing level of comfort with physician-assisted dying amongst physicians.

Wim Distelmans, who was Chairman of the Federal Control and Evaluation Commission in Belgium, was interviewed by the *New Yorker* and stated that:

We at the commission are confronted more and more with patients who are tired of dealing with the sum of small ailments – they are what we call ‘tired of life’.

...

⁴⁸ Cook, Michael, “Belgian Euthanasia: not such a big deal?”, BioEdge, 22 February 2013, http://www.bioedge.org/bioethics/bioethics_article/10401 (Accessed 30 May 2016)

See also Cohen-Almagor Raphael, “First do no harm: pressing concerns regarding euthanasia in Belgium”, *International Journal of Law and Psychiatry*, 2013, p5.

⁴⁹ Lemmens, Trudo, *The Conflict Between Open-ended Access to Physician-Assisted Dying and The Protection of the Vulnerable: Lessons from Belgium’s Euthanasia Regime in the Post-Carter Era*, (forthcoming), Catherine Regis, Lara Khoury & Robert Kouri, eds., *Key Conflicts in Health Law*, (Cowensville: Yvon Blais, 2016), p8.

⁵⁰ see Kenneth Chambaere et al, “Recent Trends in Euthanasia and Other End-of-Life Practices in Belgium”, 2015, 372:12, *New England Journal of Medicine*, p1179.

See in general also the Reports of the Federal Euthanasia Control and Evaluation Commission, which are posted by LevensEinde InformatieForum, online: <http://www.leif.be/professioneel/professionelegids/139-rapportenevaluatiecommissieeuthanasie.html>

If you ask for euthanasia because you are alone, and you are alone because you don't have family to take care of you, we cannot create family.⁵¹

In 2013, Wim Distelmans euthanised a 44 year old transgender man, Nathan Verhelst, because Verhelst was devastated by the outcome of his sex-change operation.⁵²

Lemmens reports on a number of stridently pro-euthanasia physicians in Belgium who publicly argue for a need to widen current practices and who reject basic regulatory requirements such as reporting cases to regulators or consulting a second physician.⁵³

A report by the European Institute of Bioethics warned that euthanasia has become normalised:

Initially legalized under very strict conditions, euthanasia has gradually become a very normal and even ordinary act to which patients are deemed "to have a right". In the face of certain high profile cases, the evident relaxation of the very strict conditions has caused many reactions but also a total absence of any sanctions on the part of the Commission and a very conciliatory silence from the political establishment has given rise to a feeling of impunity on the part of some concerned medical practitioners, and to a feeling of powerlessness in those worried about where things are leading.⁵⁴

4.4.2 The Netherlands

A recent article by a former review committee member in the Netherlands, Theo Boer, notes a shift in the type of patients who seek assisted dying:

... beginning in 2007, the numbers of assisted dying cases started going up by 15 percent each year. In 2014 the number of cases stood at 5,306, nearly three times the 2002 figure.

A shift has also taken place in the type of patients who seek assisted dying. Whereas in the first years the vast majority of patients—about 95 percent—were patients with a terminal disease who had their lives ended days or weeks before a natural death was expected, an increasing number of patients now seek assisted dying because of dementia, psychiatric illnesses, and accumulated age-related complaints.

Terminal cancer now accounts for fewer than 75 percent of the cases. Many of the remaining 25 percent could have lived for months, years, or even decades. In some reported cases, the suffering largely consists of being old, lonely, or bereaved.⁵⁵

⁵¹ Aviv, Rachel, "The Death Treatment", June 22 2015, *The New Yorker*, <http://www.newyorker.com/magazine/2015/06/22the-death-treatment>

⁵² Aviv, Rachel, "The Death Treatment", June 22 2015, *The New Yorker*, <http://www.newyorker.com/magazine/2015/06/22the-death-treatment>

⁵³ Lemmens, Trudo, "The Conflict Between Open-ended Access to Physician-Assisted Dying and The Protection of the Vulnerable: Lessons from Belgium's Euthanasia Regime in the Post-Carter Era" (forthcoming in Regis, Catherine, Lara Khoury and Robert Kouri, eds., *Key Conflicts in Health Law*, Cowensville: Yvon Blais, 2016). See discussion on pp32-33.

⁵⁴ European Institute of Bioethics, *Euthanasia in Belgium: 10 Years On*, 2012, p7.

⁵⁵ T de Boer, [Rushing toward death? Assisted dying in the Netherlands](#), *Christian Century*, 28 March 2016.

This normalisation manifests itself in many ways. In 2012, mobile euthanasia clinics began providing lethal injections to people free of charge at their homes in the Netherlands:⁵⁶

The launch of the so-called *Levenseinde*, or "Life End", house-call units – whose services are being offered to Dutch citizens free of charge – coincides with the opening of a clinic of the same name in The Hague, which will take patients with incurable illnesses as well as others who do not want to die at home.

The scheme is an initiative by the Dutch Association for a Voluntary End to Life (NVVE), a 130,000-member euthanasia organisation that is the biggest of its kind in the world.⁵⁷

http://www.cmq.org.uk/CMQ/2015/Nov/dutch_experiences_on_regulating.html (Accessed 10 May 2016).

See also: J Legemaate and I Bolt, [The Dutch Euthanasia Act: Recent Legal Developments](#), *European Journal of Health Law*, 20, 2013.

⁵⁶.Connolly, K, "Dutch mobile euthanasia units to make house calls", *The Guardian*, 2 March 2012; <http://www.theguardian.com/world/2012/mar/01/dutch-mobile-euthanasia-units> (Accessed 30 May 2016)

And see: Holligan, A, "Dutch offered 'euthanasia on wheels'", *BBC News Europe*, 4 March 2012: <http://www.bbc.com/news/world-europe-17230102> (Accessed 30 May 2016)

⁵⁷.Connolly, K, "Dutch mobile euthanasia units to make house calls", *The Guardian*, 2 March 2012; <http://www.theguardian.com/world/2012/mar/01/dutch-mobile-euthanasia-units> (Accessed 30 May 2016)

4.5 A growing number of cases involving vulnerable people

One of key arguments used to support the legalisation of euthanasia and assisted dying is the need to respect peoples' autonomy. The growing number of cases involving very vulnerable people or people who may not have a capacity to provide meaningful consent raises serious questions about the validity of this rationale.

4.5.1 People who feel as though they are a burden

In 2006, Dr Harvey Chochinov undertook a review of the empirical literature related to the psychological, existential and spiritual aspects of patient deaths.⁵⁸ Some key findings cited by Chochinov in relation to this issue were:

- A study of reports from family members of patients in Oregon and Washington State who expressed a wish for hastened death indicated that 59% of patients who did not discuss wanting assisted suicide and 94% of patients who did discuss wanting assisted suicide experienced distress due to feeling like a burden on others.⁵⁹ The study found that: "Data from other studies and from the Oregon Health Division supports that fear of being a burden is common in patients who die by lethal prescription."⁶⁰
- This is corroborated from survey data of caregivers in Japan.⁶¹
- In a study from Northern Ireland, 103 doctors provided case history details of patients who had requested euthanasia. Being a "burden to others" was the second most commonly cited concern of patients, being raised in 54.9% of cases.⁶²
- A study of patients who killed themselves found that many were concerned about being a burden on others: "Multiple vulnerability factors were present simultaneously in all patients. However, the loss of, and the fear of losing, autonomy and their independence and of being a burden on others were the most relevant."⁶³

A 2009 survey of 56 Oregonians who had either requested physician aid in dying (PAD) or contacted a PAD agency sought to explore the motivation for these requests. Respondents were asked to rate each of 29 possible reasons on a scale from 1 to 5 (1 being not very important through to 5 being very important). The most important reasons, with a median score of 5, included "wanting to

⁵⁸ Chochinov, Harvey Max, "Dying, Dignity, and New Horizons in Palliative End-of-Life Care", *CA Cancer Journal for Clinicians*, 2006; 56:84-103.

⁵⁹ Ganzini L, Silveira MJ, Johnston WS. Predictors and correlates of interest in assisted suicide in the final month of life among ALS patients in Oregon and Washington. *Journal of Pain Symptom Management*, 2002;24, p315.

Morita T, Sakaguchi Y, Hirai K, et al., "Desire for death and requests to hasten death of Japanese terminally ill cancer patients receiving specialized inpatient palliative care.", *Journal of Pain Symptom Management*, 2004;27:44-52. This was a survey of 500 primary caregivers with a response rate of 290. It found that one of the major reasons for desiring death and for making a request to hasten death was being a burden on others.

⁶⁰ Ganzini L, Silveira MJ, Johnston WS. Predictors and correlates of interest in assisted suicide in the final month of life among ALS patients in Oregon and Washington. *Journal of Pain Symptom Management*, 2002;24:p316.

⁶¹ Morita T, Sakaguchi Y, Hirai K, et al., "Desire for death and requests to hasten death of Japanese terminally ill cancer patients receiving specialized inpatient palliative care.", *Journal of Pain Symptom Management*, 2004;27:44-52. This was a survey of 500 primary caregivers with a response rate of 290. It found that one of the major reasons for desiring death and for making a request to hasten death was being a burden on others.

⁶² McGlade KJ, Slaney L, Bunting BP, Gallagher AG., "Voluntary euthanasia in Northern Ireland: general practitioners' beliefs, experiences, and actions", *British Journal of General Practice*, 2000;50:794-797.

⁶³ Filiberti A, Ripamonti C, Totis A, et al., "Characteristics of terminal cancer patients who committed suicide during a home palliative care program". *Journal of Pain and Symptom Management*, 2001.

control the circumstances of death”, “future poor quality of life”, “future pain” and “loss of independence”. Importantly, another reason that rated very high, with a median score of 4 was “perception of self as burden”.⁶⁴

This corroborated results from an earlier 2001 study of physician-assisted suicide in Oregon reported in the *New England Journal of Medicine* which found that 63% of patients who received a hastened death under the Dying with Dignity Act had expressed a strong sense of being burden and that “the frequency of concern about being a burden to others has increased.”⁶⁵

In the most recent report published by the Oregon Public Health Division, of the 132 deaths for which data was available, 48% listed being a burden on family, friends or caregivers as a concern.⁶⁶

Box 2: Case Study - Kate Cheney, Oregon

“Kate Cheney, an eighty-five-year-old widow, was diagnosed as terminally ill with stomach cancer. Kate wanted the option of assisted suicide in case she was in pain or if the indignities of losing control of her body functions became unbearable. Her daughter Erika, a retired nurse who had come from Arizona to care for her mother, went with Kate when she made her request for assisted suicide to her physician at Kaiser Permanente. Erika described the physician as ‘dismissive’ and requested and received a referral to another Kaiser physician. Kate’s second doctor arrange for a psychiatric consultation, a standard procedure at Kaiser. Although the psychiatrist who visited Kate at her home declined to be interviewed, the family released his report to the *Oregonian’s* reporter. The psychiatrist found that the patient did ‘not seem to be explicitly pushing for assisted suicide’ and lacked ‘the very high level of capacity to weigh options about it.’ Although the patient seemed to accept the assessment, the psychiatrist noted that the daughter became very angry.

Kaiser then suggested that the family obtain a second assessment from an outside consultant. The psychologist consulted noted that Kate had some memory defects and that her ‘choices [might have been] influenced by her family’s wishes, and that her daughter, Erika, [might have been] somewhat coercive’ but felt that Kate had the ability to make her own decision. A Kaiser administrator saw Kate and decided that she was competent and was making the decision on her own. Kate received the lethal drugs, which were put under Erika’s care.

As time went by and Kate ate poorly and became somewhat weaker, Erika and her husband needed a respite and sent Kate to a nursing home for a week. Kate ate well there, but when Erika visited Kate always asked when she would be going home. On the day she returned from the nursing home she told Erika and her husband that something had to be done, given her declining health. She had considered going permanently into a nursing home but decided against it. She told them she wanted to use the pills and asked for their help. ‘When would you like to do this?’ her son-in-law asked. ‘Now’, Kate replied. Grandchildren were contacted, those who lived nearby came over, goodbyes were said, and within a short time, with her family beside her, Kate took the pills and died.”⁶⁷

⁶⁴ Ganzini, Linda, Elizabeth Goy and Steven K. Dobscha, “Oregonians’ Reasons for Requesting Physician Aid in Dying”, *Arch Intern Med*, Vol. 169 (No. 5), March 9, 2009, p491.

⁶⁵ Sullivan AD, Hedberg K, Hopkins D., “Legalized physician-assisted suicide in Oregon, 1998-2000”, *New England Journal of Medicine*, 2001;344:605–607. The percentage of patients with concerns about being a burden on family, friends or other caregivers rose from 2/16 (12%) to 17/27 (63%).

⁶⁶ Oregon Public Health Division, Annual Reports under the Death with Dignity Act: for the most recent report see <http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year18.pdf>, p6.

⁶⁷ Foley K and Hendin H (Eds.) *The Case against Assisted Suicide, For the Right to End-of-Life Care*, Baltimore: Johns Hopkins University Press, 2002, pp156-157.

In the case of Kate Cheney, one can easily see how an elderly person could feel as though they were a burden on their family. The pressure on Kate's family was immense and her daughter and son-in-law were in desperate need of respite. However, it is also true that, as Foley and Hendin observe, "one can readily see how in the best of circumstances frail elderly patients can feel coerced to die."⁶⁸

4.5.2 Depression

Many people experiencing terminal diseases also suffer from depression. This is completely unsurprising. The prevalence of depression in people with terminal conditions raises a significant question as to how that depression interacts with decision-making. It goes without saying that experiencing depression doesn't necessarily make one unable to make sound decisions. But depression can impact on decision-making in a way that raises questions about the effectiveness of safeguards in relation to irreversible choices.

Depression is common amongst those seeking euthanasia and assisted suicide. In a study of 138 cancer patients with an estimated life expectancy of 3 months or less, a strong connection was found between depression and a request for euthanasia. Specifically, a patient was 4.1 times more likely to request euthanasia if depressed than if not depressed.⁶⁹

A study of suicide victims who had suffered from cancer found that depressive syndromes were present in 80 per cent of cases. "Only a small minority of cancer suicides seem to occur in the absence of mental disorders."⁷⁰

In a study of 44 terminally ill patients by Brown et al, 34 had never wished death to come early and ten were either suicidal (3) or desired an early death (7). All ten of the patients who desired an early death were found to be suffering from clinical depressive illness.⁷¹

Ganzini et al, in a broad ranging review of instances of assisted dying in Oregon, found that twenty percent of the patients had symptoms of depression.⁷²

These studies raise questions about what safeguards need to be in place in legalised euthanasia or assisted suicide regimes to protect people from making decisions that might be affected in the short term by a depressive mood that might be manageable or treatable with additional support.

Some argue that euthanasia and assisted suicide are suitable in cases of treatment-resistant depression. Even in these cases, treatment options are often available. A study of the longer-term outcomes for patients with confirmed treatment-resistant depression examined the outcomes between 8 to 34 months following treatment in a specialist in-patient centre. The study included 118 participants. The key result was that the majority of participants (60.2%) were in full remission

⁶⁸ Ibid, p157.

⁶⁹ Van der Lee, Marije, Johanna van der Bom, Nikkie B. Swarte, A. Peter Heintz, Alexander de Graeff and Jan van den Bout, "Euthanasia and Depression: A Prospective Cohort Study Among Terminally Ill Cancer Patients", *Journal of Clinical Oncology*, Vol 23, Number 27, 2005, pp6608-6609.

⁷⁰ Henriksson MM, Isometsa ET, Hietanen PS, Aro HM, Lonnqvist JK., "Mental disorders in cancer suicides", *Journal Affective Disorders*, 1995;36:11-20.

⁷¹ Brown JH, Henteleff P, Barakat S, Rowe CJ., "Is it normal for terminally ill patients to desire death?", *Am J Psychiatry* 1986;143:208-11.

⁷² Ganzini Linda, Heidi Nelson, Terri Schmidt, Dale Kraemer, Molly Delorit and Melinda Lee, "Physicians' Experiences with Oregon Death with Dignity Act", *New England Journal of Medicine*, Volume 342, Number 8, p559.

following specialist care and that nearly half of the total sample (48.3%) maintained full remission for at least 6 months.⁷³

While this does not mean that all cases of treatment-resistant depression can be fully treated, it does suggest that great care needs to be taken where a person is suffering from depression and is seeking either euthanasia or assisted dying. Given the range of treatments currently available and the ever improving prospects for treatment over time, the risk of allowing someone to choose death when realistic treatment options are available is a real one.

A number of studies have shown that physicians find it difficult to diagnose depression in patients with terminal conditions, let alone to determine whether that depression is impairing judgement.⁷⁴ Foley and Hendin argue that the Ganzini et al study cited above of physicians administering lethal injections in Oregon suggests potential difficulties in diagnosis. In that study of 143 cases, 20 per cent were identified as having depression which Foley and Hendin argue is materially well below the more commonly established rate of approximately 60 per cent or more.⁷⁵ This suggests that at, in at least some cases in the survey, depression may have been undiagnosed.

In 2015, *The New Yorker* examined the high profile case of Godelieva De Troyer in considerable detail.⁷⁶ This is a complex case from Belgium involving a woman who had suffered from severe depression over a long period of time. During a period of alienation from her adult children, she was euthanised without their knowledge. This case has achieved a high degree of public attention both within Belgium and internationally as it highlights the particularly complex circumstances that can arise when euthanasia is carried out on a person with a mental health condition.

One of the main reasons that the case has generated public debate is the campaign that was subsequently waged by her son. He has challenged the appropriateness of a person being euthanised without family members being consulted. He argues that it was particularly inappropriate in Godelieva's case given that her depression arose, in part, as a result of estrangement from her family. A reconciliation might have been a key element in her recovery. Issues relating to consultation with family members in cases of mental health care decisions arise more broadly than in cases of euthanasia. But these issues are particularly pronounced in euthanasia given the irreversibility of the decision.

A second issue relating to this case that has caused public controversy is a review of Godelieva's medical file that was undertaken by Dr Georges Casteur, a former president of the provincial council of the doctors of West Flanders. His review found that Godelieva had "struggled to find three doctors who would say that she had an incurable illness, as the law required. One psychiatrist wrote that her desire for euthanasia was 'not mature', because she has 'ups and downs'". According to the reviewing psychiatrist, a second doctor concluded that she could still be helped and that "when

⁷³ Fekadu, Abebaw, Lena Rane, Sarah Wooderson, Kalypso Markopolou and Lucia Poon, "Prediction of Longer-term Outcome of Treatment-Resistant Depression in Tertiary Care", (2012) 201, *British Journal of Psychiatry*, 369. Some other studies show lower rates.

⁷⁴ Foley K and Hendin H (Eds.) *The Case against Assisted Suicide, For the Right to End-of-Life Care*, Baltimore: Johns Hopkins University Press, 2002, p151.

⁷⁵ Ibid, p151. Foley and Hendin are referring to results from Ganzini et al in the *New England Journal of Medicine*.

⁷⁶ Aviv, Rachel, "The Death Treatment", June 22 2015, *The New Yorker*, <http://www.newyorker.com/magazine/2015/06/22the-death-treatment>

Godelieva discussed her grandchildren she became emotional and expressed doubts about her decision to die.”⁷⁷

The purpose of raising this case is not to dwell on the particulars of Godelieva’s situation, but rather to highlight the difficulties in diagnosis and treatment in cases involving depression and mental health issues more generally. Jurisdictions such as Belgium and the Netherlands have more stringent safeguards in place where there is a mental health condition, but the effectiveness of these safeguards in practice is not proven.

4.5.3 Mental Illness

This paper will not examine the merits of whether a scheme should permit euthanasia or assisted suicide where a patient is suffering from a mental illness. At the very least, it is worth noting that in such situations additional care should be taken as diagnosis will often be challenging and it will usually be more difficult to clearly establish consent. The growing prevalence of euthanasia and assisting dying for people with mental illness in at least some jurisdictions raises concerns about the effectiveness of safeguards.

The Belgian legislation allows those experiencing mental suffering to access physician assisted dying but includes additional safeguards for people in this category. This includes a detailed consultation with a third physician and a mandatory one month waiting period between the request and the life-ending act.

The proportion of euthanasia deaths involving neuropsychiatric disorders has increased sharply in Belgium over the past decade, from 1.2% of cases in 2004/05 to 2.8% in 2010/11 (58 cases) and 3.7% of cases in 2013/14 (67 cases).⁷⁸ Table 4 contains the number of instances of euthanasia in Belgium over recent years as reported to the Belgian legislature.

Table 4: Number of cases of euthanasia for neuropsychiatric conditions in Belgium⁷⁹

Source	Years covered by report	Number of cases of neuropsychiatric conditions
Second report	2004 and 2005	9 ⁸⁰
Third report	2006 and 2007	13 ⁸¹
Fourth report	2008 and 2009	62
Fifth report	2010 and 2011	105

⁷⁷ Aviv, Rachel, “The Death Treatment”, June 22 2015, *The New Yorker*, <http://www.newyorker.com/magazine/2015/06/22the-death-treatment>

⁷⁸ Lemmens, Trudo, The Conflict Between Open-ended Access to Physician-Assisted Dying and The Protection of the Vulnerable: Lessons from Belgium’s Euthanasia Regime in the Post-Carter Era, (forthcoming), Catherine Regis, Lara Khouri & Robert Kouri, eds., *Key Conflicts in Health Law*, (Cowensville: Yvon Blais, 2016), p39.

⁷⁹ Montero, Professor Etienne, Affidavit to Lee Carter v The Attorney General of Canada et al, Supreme Court of Canada, No. 35591, p51.

⁸⁰ This included three cases of Alzheimer’s disease, one case of Huntington’s disease, one case of Creutzfeldt-Jacob disease and four cases of unyielding depression.

⁸¹ Nine cases of neuropsychiatric conditions (dementia or depression) in addition to four for people with neuropsychiatric conditions for whom death was not expected in the short term.

In the Netherlands, recent data from reports of the Regional Euthanasia Review Committees points to a growing number of cases of euthanasia in cases of mental illness and dementia. Table 5 contains the number of cases of mental illness and dementia over the period 2012-2015.

While the number of cases in each category is coming off a low base, the rapid CAGR rate suggests that number of cases in each category could be very large in the not too distant future. There is no reason to think that growth rates in either category will taper off given what we observe in growth rates in the overall number of cases both in the Netherlands and other major jurisdictions.

Table 5: Number of cases of euthanasia for mental illness or dementia in Netherlands⁸²

Year	Mental Illness (Cases)	Dementia (Cases)
2012	14	42
2013	42	97
2014	41	81
2015	56	109
Growth rate: (CAGR 2012-2015)	59%	37%

As is noted above, when the Belgian Act on euthanasia was being debated and adopted, it was stated repeatedly that patients with psychiatric disorders, dementia or depression would be excluded from the Act.⁸³ However, as in the Netherlands, there has been a rapid growth in this category over recent years.

In 2007, the *Netwerk Depressie Vlaanderen*, a Flemish association that provides support to people suffering from depression, stated that: “The door to euthanasia is open for thousands of depressed and suicidal people to kill themselves legally.”⁸⁴

Dealing with requests for euthanasia or assisted suicide from people with mental illness is particularly challenging for medical practitioners. Kim et al undertook a detailed review of 66 cases of euthanasia and assisted suicide involving psychiatric conditions in the Netherlands between 2011 and 2014. Two senior psychiatrists reviewed reports provided by the Dutch regional euthanasia review committees up to 1 June 2015. They found that:

- Most patients had chronic, severe conditions with histories of attempted suicides and psychiatric hospitalisations.
- A range of conditions were present including: depression; personality disorders; psychotic, post-traumatic stress or anxiety; neurocognitive and eating disorders; as well as prolonged grief and autism.
- 27% (n=18) of patients received euthanasia or assisted suicide from physicians new to them.

⁸² See Dutch Regional Euthanasia Review Committee Annual Reports.

⁸³ Montero, Professor Etienne, Affidavit to Lee Carter v The Attorney General of Canada et al, Supreme Court of Canada, No. 35591, p51.

⁸⁴ Statement made in the article “Qatre cas pour depression majeure irreductible”, La Libre Belgique, 2 February 2007. See translation in Montero, Professor Etienne, Affidavit to Lee Carter v The Attorney General of Canada et al, Supreme Court of Canada, No. 35591, p51.

- Of the 18 physicians that were new to patients, 14 of these were from the End-of-Life Clinic, a mobile euthanasia clinic.⁸⁵ In 2012, the NVVE (Dutch Association for a Voluntary End to Life) created the End-of-life Clinic and started making “house calls” via mobile euthanasia units that respond to the wishes of patients whose regular doctors have refused to carry out their wishes.⁸⁶

Kim et al conclude that the “granting of their EAS [euthanasia or assisted suicide] requests appears to involve considerable physician judgment, usually involving multiple physicians who do not always agree (sometimes without independent psychiatric input)”.⁸⁷

The difficulty of evaluating suicidal patients with serious medical illness is explored by Hamilton et al. They argue that there are competing paradigms: the traditional model; and the assisted suicide competency model.⁸⁸

In the *Harvard Medical School Guide to Suicide Assessment and Intervention*⁸⁹, Hendin argues that medically ill suicidal patients are no different from other suicidal individuals. “Although physical illness may be a precipitating cause of despair, these patients usually suffer from treatable depression and are always ambivalent about their desire for death.”⁹⁰

Hamilton et al argue that “when it comes to treatment, the approach in this population emphasizes an effort to ‘understand and relieve the desperation that underlies the request for assisted suicide.’ To do so, the clinician must resist assuming the role of ‘gatekeeper’, someone who would focus on issues of competence alone.”⁹¹

This approach, they argue, can be contrasted with the assisted suicide competency model. One example of the alternative approach is contained in Oregon’s assisted suicide guidebook which states that:

The mental health consultation as outlined in the Oregon Act, is a form of a capacity or competence evaluation, specifically focused on capacity to make the decision to hasten death by self-administering a lethal dose of medication.⁹²

In the assisted suicide competency model, there is no obligation to treat depression or mental illness where it is found.

⁸⁵ Kim, Scott Y. H., Raymond De Vries and John Peteet, “Euthanasia and Assisted Suicide of Patients with Psychiatric Disorders in the Netherlands 2011 to 2014”, *JAMA Psychiatry*, 2016: 73(4), 362-368.

⁸⁶ <http://www.theguardian.com/world/2012/mar/01/dutch-mobile-euthanasia-units> ; 1 March, 2012.

See also an article from Spiegel re the controversial practice: <http://www.spiegel.de/international/controversy-over-dutch-mobile-euthanasia-teams-in-the-netherlands-a-822484.html> ; March 22, 2012.

⁸⁷ Kim, Scott Y. H., Raymond De Vries and John Peteet, “Euthanasia and Assisted Suicide of Patients with Psychiatric Disorders in the Netherlands 2011 to 2014”, *JAMA Psychiatry*, 2016: 73(4), 362-368.

⁸⁸ Hamilton, Gregory and Catherine Hamilton, “Competing Paradigms of Response to Assisted Suicide Requests in Oregon”, *American Journal of Psychiatry*, 162:6, June 2005, p1060.

⁸⁹ Hendin, J, “Suicide, assisted suicide, and euthanasia”, *Harvard Medical School Guide to Suicide Assessment and Intervention*, edited by Jacobs DG, San Francisco, Jossey-Bass, 1999, pp540-560.

⁹⁰ Hamilton, Gregory and Catherine Hamilton, “Competing Paradigms of Response to Assisted Suicide Requests in Oregon”, *American Journal of Psychiatry*, 162:6, June 2005, p1060.

⁹¹ Hamilton, Gregory and Catherine Hamilton, “Competing Paradigms of Response to Assisted Suicide Requests in Oregon”, *American Journal of Psychiatry*, 162:6, June 2005, p1060. See also Foley K and Hendin H (Eds.) *The Case against Assisted Suicide, For the Right to End-of-Life Care*. Pp192-209. Baltimore: Johns Hopkins University Press, 2002, p152.

⁹² Goy, Elizabeth, Linda Ganzini and Tony Farrenkopf, “Mental Health Consultation”, in Dunn, Patrick et al (eds), *The Oregon Death with Dignity Act: A Guidebook for Health Care Professionals*, 2008 edition, Chapter 9.

The differences between the approach to dealing with patients suffering from depression and mental illness in Oregon assisted suicide consultations (and in similar jurisdictions) as compared to more traditional treatment clinical models is telling. It is potentially problematic in an area where there is still considerable disagreement between experts as to the relationship between depression, mental health issues and competence.

4.5.4 Cases in which explicit consent is not given

One of the difficulties of drawing conclusions in relation to life-ending acts without explicit patient request is the lack of clear data. In a large-scale death certificate survey, Chambaere et al find that “life-ending acts without explicit request are significantly different from those provided in euthanasia and similar to those provided in standard palliative care.”⁹³ This suggests that some of the worst fears that have been expressed in this area are based more on poor reporting than systemic abuse.

However, they also argue that legalisation of euthanasia or physician-assisted dying did not put an end to the practice of non-voluntary or involuntary termination of life (as argued elsewhere in this paper) and that: “we recommend a more nuanced view of life-ending acts without explicit patient request in the debate on physician-assisted dying.”⁹⁴

Some advocates claim that legalisation of either euthanasia or assisted dying will bring practices such as euthanasia without consent into the open. Seale examines end-of-life decisions in the UK and concludes that the rate of this type of end-of-life decision-making is sufficiently low that: “in the UK, this argument cannot be made.”⁹⁵

In contrast, it appears that this type of euthanasia has not disappeared from countries which have legalised euthanasia or assisted suicide, with relatively high rates persisting in Belgium. A study in *the Lancet* by Van der Heide et al undertook surveys in six European countries to contrast end-of-life decision making. It found that ending of a patient’s life without request occurred at rates ranging from 0.06% (Italy) through to 1.50% (Belgium).⁹⁶ Two countries with the highest rates of this type of end-of-life (Belgium at 1.5% and the Netherlands with 0.60%) allowed the practice of euthanasia and assisted dying.

Moreover, as will be argued below, it is clear that wherever the legal line is drawn, activity occurs in the grey area around that line that is difficult to monitor.

⁹³ Chambaere, Kenneth, Jan Bernheim, James Downar and Luc Deliens, “Characteristics of Belgian ‘life-ending acts without explicit patient request’: a large-scale death certificate survey revisited”, *CMAJ Open*, 2(4), 2014, pE264.

⁹⁴ Chambaere, Kenneth, Jan Bernheim, James Downar and Luc Deliens, “Characteristics of Belgian ‘life-ending acts without explicit patient request’: a large-scale death certificate survey revisited”, *CMAJ Open*, 2(4), 2014, pE262.

⁹⁵ Seale, C, “National Survey of end-of-life decisions made by UK medical practitioners”, *Palliative Medicine*, 2006, 20:3-10.

⁹⁶ Van der Heide A., L Deliens, K Faisst, T Nilstun, M Norup, E Paci *et al*, “End-of-life decision-making in six European countries: descriptive study”, *the Lancet*, 2003, 362, p347.

See also: K. Meeussen, L. Van den Block, N. Bossuyt *et al.*, “Physician reports of medication use with explicit intention of hastening the end of life in the absence of explicit patient request in general practice in Belgium” , *BMC Public Health*, 10 (2010), p. 186.

4.5.5 Patients receiving inadequate pain relief or palliative care

Many situations in which a person requests a hastening of death involve pain management or palliative care that fall short of best practice. Before legislating for euthanasia or assisted suicide, it would be appropriate to provide greater support to health care providers dealing with patients at the end of life.

Cases involving inadequate pain management

The Committee received considerable expert evidence that best practice medical treatment and palliative care can now effectively manage pain in almost all cases. Occasionally, best practice is not followed. The best response to the occasional failure to maintain best practice is to provide appropriate resourcing to the health care system – including training for health practitioners - and to ensure that processes to monitor the quality of end-of-life care are adequate.

Dr Natasha Michael, Director of Palliative Care at Cabrini Health argued that, many of the instances of poor end-of-life care that are used to justify euthanasia or assisted suicide reflect practitioners who:

... practice outside of the scope of their training and experience and neither have the knowledge, experience or skill to assist those who suffer. The ongoing under-resourcing of psychosocial support to patients and family needs urgent attention in palliative care and in end-of-life care. The association between the expression of a desire for death and depression, anxiety and demoralisation is well-documented in international research. However, there remains poor availability of key staff in clinical psychology, liaison psychiatry and social work services in our populations.⁹⁷

Cases involving inadequate palliative care: Oregon

In a study published in the *New England Journal of Medicine*, Ganzini, Nelson, Schmidt, et al. reported the results of an extensive survey of physicians eligible to prescribe lethal medications under the Oregon Death with Dignity Act. Of the 2,649 physicians responding (65% response rate), 144 had received a total of 221 requests for prescriptions of lethal medications. Complete information was received for 143 patients, including the final outcome for those patients.⁹⁸

In the case of 68 patients, the treating physician implemented at least one substantive intervention, including: control of pain or other symptoms; referral to a hospice; a mental health, social work, chaplaincy or palliative care consultation; or a trial of antidepressant medication. Of the patients who experienced a substantive intervention, 31 out of 67 (46%) changed their minds about wanting a prescription for lethal medication as opposed to 11 out of 73 (15%) for whom no substantive

⁹⁷ Dr Natasha Michael, Director of Palliative Care, Cabrini Health, *Transcript of evidence*, 16 September 2016, pp7-8.

⁹⁸ Ganzini Linda, Heidi Nelson, Terri Schmidt, Dale Kraemer, Molly Delorit and Melinda Lee, "Physicians' Experiences with Oregon Death with Dignity Act", *New England Journal of Medicine*, Volume 342, Number 8, p557.

intervention was given.⁹⁹ This material difference in outcomes indicates how dangerous it can be if any patients fail to access all best practice treatment interventions when they are in a vulnerable situation and considering suicide or euthanasia.

The 2016 Report of the Oregon Health Division indicates that 28.7% expressed inadequate pain control or a concern about it as a reason for wanting assisted suicide.¹⁰⁰ This was the second least commonly cited reason in 2015.

It would be useful to know, of the 28.7%, what proportion were experiencing unendurable pain at the time the lethal dose was prescribed and administered and what proportion were suffering from an anticipation of future pain. It would also be useful to know, of those patients experiencing unendurable pain at the time the dosage was administered, how many were not benefiting from best practice pain relief of palliative care.

Advocates of euthanasia and assisted dying often point to the potential for legalised regimes to provide people with comfort by providing them with the assurance that they will be able to opt for a painless death if they wish to. Yet how many people under the assisted dying regime in Oregon (and similar regimes) secure access to lethal drugs out of a fear of future unbearable pain only to use those drugs before they have explored best practice palliative care options? Given current reporting arrangements, it is impossible to know with confidence.

Cases involving inadequate palliative care: the Northern Territory

The legalisation of euthanasia in the Northern Territory was accompanied by a number of safeguards that advocates of euthanasia and assisted suicide claim can protect vulnerable people in practice, including that:

- Under the legislation, an opinion from a second medical practitioner was required to verify the existence and terminal nature of the patient's illness. The second medical practitioner was required to have "special expertise in the illness [being experienced by the patient] and qualifications in a medical specialty recognised by fellowship in a specialist college in Australia."¹⁰¹
- If the first doctor did not have special qualifications in palliative care, a third doctor with such expertise and qualifications was required to give information to the patient on the availability of palliative care.¹⁰²
- A psychiatrist was required to examine the patient to certify that he or she did not have "a treatable clinical depression."¹⁰³

The outcomes of this brief episode of legalising euthanasia are highly instructive as it is the only example of legalisation in Australia to date.

⁹⁹ Ganzini Linda, Heidi Nelson, Terri Schmidt, Dale Kraemer, Molly Delorit and Melinda Lee, "Physicians' Experiences with Oregon Death with Dignity Act", *New England Journal of Medicine*, Volume 342, Number 8, p560.

¹⁰⁰ Oregon Public Health Division, *Oregon Death with Dignity Act: 2015 Data Summary*, February 4 2016, p6.

¹⁰¹ Kissane, David, "Deadly Days in Darwin", in Foley K and Hendin H (Eds.) "The Case against Assisted Suicide, For the Right to End-of-Life Care", pp192-209. Baltimore: Johns Hopkins University Press, 2002, p193.

¹⁰² Ibid, p194.

¹⁰³ Ibid, p194.

The experiences of people whose lives ended under the Northern Territory regime casts doubt on the effectiveness of the types of safeguards proposed in the Majority Report. During the 9 months that euthanasia was legal in the Northern Territory (July 1996 – March 1997), seven people made formal use of the Rights of the Terminally Ill (ROTI) Act, four of whom died.¹⁰⁴ All seven patients had cancer, most at an advanced stage.

In a paper by Kissane, Street and Nitschke¹⁰⁵, it was found that three of the seven patients were socially isolated and depressive symptoms were present in four of the seven.¹⁰⁶ Failure of pain management did not appear to be the motivation for the patients. Of the seven patients, four had controlled pain and the remaining three did not have prominent pain.¹⁰⁷ This is in contrast to the way this issue is often framed by advocates of euthanasia and assisted dying.

The requirement that there be a consensus as to whether the patient was terminal was problematic. There was a consensus that the patient was terminal in four cases, a lack of consensus in two cases and the patient was not terminal in one case.¹⁰⁸ In one instance, an oncologist gave a prognosis of 9 months and a dermatologist and local oncologist both judged that the patient was not terminal.

The ROTI Act contained a requirement that a psychiatrist confirm that the patient was not suffering from a treatable clinical depression. “Confirmation was not easy since patients perceived such a mandatory assessment as a hurdle to overcome.”¹⁰⁹

To what extent was the psychiatrist trusted with important data and able to build an appropriate alliance that permitted a genuine understanding of a patient’s plight? In case 1, there was important background detail about the death of one child and alienation from another, which was withheld during the psychiatric assessment. These experiences may have placed the patient in a lonely, grieving, demoralised position: an unrecognised depression may have led to suicide.

Four of the seven cases had symptoms of depression, including reduced reactivity, lowered mood, hopelessness, and suicidal thoughts. Case 4 was receiving treatment for depression, but no consideration was given to the efficacy of dose, change of medication, or psychotherapeutic management. PN judged this patient as unlikely to respond to further treatment. Nonetheless, continued psychiatric care appeared warranted—a psychiatrist can have an active therapeutic role in ameliorating suffering rather than being used only as a gatekeeper to euthanasia. Ganzini and colleagues¹⁷ showed that only 6% of psychiatrists in Oregon, USA, thought that they could be a competent gatekeeper after a single assessment of a patient.¹¹⁰

¹⁰⁴ Kissane, David, Annette Street and Philip Nitschke, “Seven Deaths in Darwin: case studies under the Rights of the Terminally Ill Act, Northern Territory, Australia”, *The Lancet*, Vol. 352, October 3 1998.

¹⁰⁵ This paper, which appeared in *the Lancet*, was based upon, inter alia, 18 hours of interviews with Nitschke by Professor David Kissane, a psychiatrist and professor of palliative care and Annette Street, a medical sociologist. In addition, the authors had access to documents from the coroner’s court, public texts created by the patients and other public commentary (eg in the media).

¹⁰⁶ Kissane, David, Annette Street and Philip Nitschke, “Seven Deaths in Darwin: case studies under the Rights of the Terminally Ill Act, Northern Territory, Australia”, *The Lancet*, Vol. 352, October 3 1998, p1098. Two had depressive symptoms (one of whom was on anti-depressants), one had a history of depression and was experiencing suicidal thoughts, and another was suicidal (this person ultimately died as a result of suicide).

¹⁰⁷ *Ibid*, p1098.

¹⁰⁸ *Ibid*, p1099.

¹⁰⁹ *Ibid*, p1101.

¹¹⁰ *Ibid*, pp1101.

In a follow up article, Professor Kissane examined each of the seven cases briefly summarised above. He found that demoralisation, which could at least partly be managed, played a significant role:

Review of these patients' stories highlighted for me the importance of demoralization as a significant mental state influencing the choices these patients made. It is likely that the mental state of demoralization influenced their judgement, narrowing their perspective about available options and choices. Furthermore, demoralized patients may not make a truly informed decision in giving medical consent.

The prognostic language within oncology that designates 'there is no cure' is one potential cause of demoralization in these patients, a cause that be avoided by more sensitive medical communication with those who are seriously ill.¹¹¹

Kissane also found that other perceptions were common in patients, most of which were manageable through effective medical and palliative care:

... this Australian cohort considered concern about loss of dignity, becoming dependent on others, and potentially being a burden as prominent reasons for the request for euthanasia. ...

Research has repeatedly shown how quality of life is appraised differently by patient, caregiver and clinician. A patient with cancer can adjust to the experience of gradual frailty over time, so long as adequate reassurance is given about the thoroughness of care long the way.¹¹²

The experience of euthanasia in the Northern Territory demonstrates that a regime with what are typically considered to be strong safeguards can fail vulnerable people. In the Northern Territory, people who experienced social isolation, isolation from family, depression and demoralisation were not given the best possible treatment.

4.5.6 Summary of evidence in relation to vulnerable people

There is considerable evidence that many vulnerable people will be put into a difficult position if euthanasia or assisted suicide are choices that become a standard part of the set of treatment options available at the end-of-life.

The House of Lords Select Committee on Ethics came to a similar overall conclusion:

... it would be next to impossible to ensure that all acts of euthanasia were truly voluntary and that any liberalisation of the law was not abused.

vulnerable people—the elderly, lonely, sick or distressed—would feel pressure, whether real or imagined, to request early death¹¹³

¹¹¹ Kissane, David, "Deadly Days in Darwin", in Foley K and Hendin H (Eds.) "The Case against Assisted Suicide, For the Right to End-of-Life Care", pp192-209. Baltimore: Johns Hopkins University Press, 2002, p203.

¹¹² Ibid, p204.

¹¹³ House of Lords, *Report of the Select Committee on Medical Ethics*, House of Lords Papers Number 21, 1993-94, paras 238-239.

4.6 The widespread failure of safeguards

The Majority Report asserts that the evidence is “clear” that safeguards work in jurisdictions with legalised euthanasia and assisted suicide. A balanced reading of the evidence would lead one to conclude that such an unequivocal statement is not true.

4.6.1 Systemic non-reporting

A requirement to report instances of euthanasia and assisted suicide is seen by some advocates as a key strength of a legalised regime. They argue that it will bring opaque practices more into the open. The experience in Belgium suggests otherwise.

In Belgium, mandatory notification of euthanasia to the Federal Control and Evaluation Commission is a cornerstone of the regulatory arrangements. However, recent reports suggest that around half of all euthanasia cases are not reported.¹¹⁴ In one study, physicians who did not report cases of euthanasia provided the following responses:

- Did not perceive their action to be euthanasia 77%
- Too much of an administrative burden 18%
- That legal due care requirements had not been met 12%
- That euthanasia is a private matter 9%
- Possible legal consequences 2%¹¹⁵

The high rate of non-reporting and the reasons given are a matter of serious concern and raise doubts about the effectiveness of official oversight.

While the rate of non-reporting is falling in the Netherlands, it appears to be of a similar magnitude to that found in Belgium.¹¹⁶

A low rate of reporting could potentially lead to serious consequences. A cross sectional analysis of reported and unreported euthanasia cases provided evidence that unreported cases were generally dealt with less carefully than reported cases. Specifically, in unreported cases: a written request for euthanasia was more likely to be absent; independent physicians and caregivers specialising in palliative care were consulted less often; the life ending act was more likely to be performed with opioids or sedatives; and the drugs were more often administered by a nurse, not a physician as required.¹¹⁷

¹¹⁴ T. Smets, J. Bilsen, J. Cohen, M.L. Rurup, L. Deliens, “Legal euthanasia in Belgium: Characteristics of all reported euthanasia cases”, *Medical Care*, 48 (2), 2010, February, pp. 187–192.,

T. Smets, J. Bilsen, J. Cohen, M.L. Rurup, F. Mortier, L. Deliens, “Reporting of euthanasia in medical practice in Flanders, Belgium: Cross sectional analysis of reported and unreported cases”, *BMJ*, 341 (2010), p. c5174.

¹¹⁵ Multiple answers are possible, which is why the various categories sum to more than 100 per cent. Smets T., J. Bilsen, J. Cohen, M.L. Rurup, F. Mortier, L. Deliens, “Reporting of euthanasia in medical practice in Flanders, Belgium: Cross sectional analysis of reported and unreported cases”, *BMJ*, 341 (2010), p. c5174.

¹¹⁶ Foley K and Hendin H (Eds.) *The Case against Assisted Suicide, For the Right to End-of-Life Care*, Baltimore: Johns Hopkins University Press, 2002.

¹¹⁷ Smets T., J. Bilsen, J. Cohen, M.L. Rurup, F. Mortier, L. Deliens, “Reporting of euthanasia in medical practice in Flanders, Belgium: Cross sectional analysis of reported and unreported cases”, *BMJ*, 341 (2010), p. c5174.

The FCEC itself has stated that it is “not capable of assessing the proportion of declared cases of euthanasia compared with the number of real cases which have actually taken place.”¹¹⁸

There are numerous high-profile and well-documented cases of actions beyond the scope of the law in Belgium that are neither being reported nor referred to prosecutor. One recent example was a public interview given by Dr Mark Cosyns in which he concedes that he routinely fails to report and in which he details a recent case of euthanasia that was of questionable compliance.¹¹⁹ As noted above, Carine Brochier reports of a physician who stated that he routinely fails to declare instances of euthanasia.¹²⁰

In Oregon, low rates of reporting are a consequence of a regulatory regime that does not require sufficient scrutiny. According to Foley and Hendin, the Oregon Health Division has interpreted its mandate narrowly:

OHD limits its yearly reports to general epidemiological data and collects limited information from physicians who have prescribed lethal medication. Physicians who declined to prescribe the lethal medication, as well as nurses and social workers who cared for patients, are not interviewed. ... There is no provision for an independent evaluator or researcher to study whatever data are available. This OHD process has presented a full and open discussion.¹²¹

4.6.2 Confusion amongst physicians

A survey conducted among physicians in Belgium seven years after the legalisation of euthanasia demonstrated that there was little consensus among physicians as to how to label hypothetical end-of-life decisions or what reporting obligations attach to such decisions. The study was based on a survey of 3,006 physicians who had graduated in their area of specialty at least 12 months prior to the survey.

¹¹⁸ Federal Control and Evaluation Commission, *Annual Report*, 2002-2003.

¹¹⁹ Lemmens, Trudo, *The Conflict Between Open-ended Access to Physician-Assisted Dying and The Protection of the Vulnerable: Lessons from Belgium's Euthanasia Regime in the Post-Carter Era*, (forthcoming), Catherine Regis, Lara Khoury & Robert Kouri, eds., *Key Conflicts in Health Law*, (Cowensville: Yvon Blais, 2016), p25 - See for example: an interview in *De Standaard* with Dr. Mark Cosyns, a palliative care specialist who has performed many PADs. When he is asked “Dr. Cosyns, you are still not reporting euthanasia to the Commission?” his answer is: “No, not when they are our own patients. I do everything on the basis of the Act on Patient's Rights [another piece of legislation]. We also don't have to justify each time we do an operation why this doesn't constitute assault.” [“Nee, niet als het om onze eigen patiënten gaat. Ik doe alles op basis van de wet op de patiëntenrechten. We moeten toch ook niet voor elke operatie verantwoorden dat we geen opzettelijke slagen en verwondingen toebrengen”] Veerle BEEL and Lieven SIOEN, “In de VS zat ik al lang achter de tralies. En jij samen met mij” [In de VS I'd already be in prison a long time ago. And you with me], *De Standaard*, 21 December 2013, online:

<http://www.standaard.be/cnt/dmf20131219_00896009>. In another interview, he admits, among other things, to have provided PAD to an elderly couple. “One of them” —to use his own words — “because of medical, terminal reasons and the other because of the psychological suffering of being old and having to continue living on her own after having lived nearly in symbiosis” [my translation of: “De ene om medische, terminale redenen en de ander omwille van het psychisch lijden van oud zijn en alleen verder te moeten na bijna in symbiose geleefd te hebben”] quoted in Fred VERBAKEL, “Niets is zo natuurlijk als sterven”, (2009) 2:4 *Relevant* 5, 6, available online: <https://www.nvve.nl/files/8513/8753/0895/Relevant_2009-2.pdf>.

¹²⁰ Cook, Michael, “Belgian Euthanasia: not such a big deal?”, BioEdge, 22 February 2013, http://www.bioedge.org/bioethics/bioethics_article/10401 (Accessed 30 May 2016)

See also Cohen-Almagor Raphael, “First do no harm: pressing concerns regarding euthanasia in Belgium”, *International Journal of Law and Psychiatry*, 2013, p5.

¹²¹ Foley K and Hendin H (Eds.), *The Case against Assisted Suicide, For the Right to End-of-Life Care*, Baltimore: Johns Hopkins University Press, 2002, pp144-145.

The report found considerable confusion in relation to classification of clear hypothetical situations:

... there is a lack of agreement among physicians in Belgium about the classification of euthanasia and other ELDs, and about which cases must be reported as euthanasia to the Federal Review Committee. Seven years after implementation of the euthanasia law in Belgium, 2 out of 10 physicians, likely to be involved in the care of dying patients, did not label a hypothetical case in which a physician ends the life a patient at that patient's explicit request using neuromuscular relaxants as 'euthanasia'. Three out of 10 physicians did not know that the case had to be reported to the Federal Review Committee.

Most physicians labelled the euthanasia case in which the physician ends the life of a patient at that patient's explicit request using morphine (case 3) as 'intensification of pain and symptom treatment' (39%) or as 'palliative/terminal sedation' (37%); only 21% of physicians labelled this case as 'euthanasia'.¹²²

Even among those physicians who labelled instances of euthanasia correctly, a considerable number did not know that they had an obligation to report such cases. This is likely to be a contributory factor to the low overall rates of reporting observed in Belgium.

4.6.3 The difficulty of deciding whether a case is terminal

Some euthanasia and assisted dying regimes limit eligibility to terminal cases. This might involve specifying a time-limit (e.g. a patient's prognosis is that they are likely to die within, say, 6 months) while others are more open-ended. In practice, deciding whether a patient is "terminal" is extremely difficult. Physicians find it difficult to put specific time estimates on many patients' conditions and, unsurprisingly, often disagree with each other.

In Oregon, a patient is only eligible for assisted suicide if they are terminally ill, with less than six months to live. When surveyed, over 50 per cent of Oregon physicians indicated that they were not confident that they could make such a prediction.¹²³ It is unclear at present how this uncertainty is communicated to patients seeking assisted suicide.

Compounding this difficulty in Oregon is the fact that the proportion of cases involving advanced cancer is trending down. There is an increasing tendency for patients seeking lethal prescriptions to have conditions with a less predictable future trajectory such as ALS (16% in 2014), chronic lower respiratory disease, Multiple Sclerosis, Parkinson's disease, diabetes and heart disease.¹²⁴ Of the 105 patients who took lethal drugs in 2014, 11 had been diagnosed as having less than six months to live in 2012 or 2013.¹²⁵

¹²² Smets, T., J. Cohen, J. Bilsen, Y Van Wesemael, M. Rurup and L. Deliens, "The labelling and reporting of euthanasia by Belgian physicians: a study of hypothetical cases", *The European Journal of Public Health*, 2010, 1-8. See page 6 for the discussion of results.

¹²³ Foley K and Hendin H (Eds.) *The Case against Assisted Suicide, For the Right to End-of-Life Care*. Pp192-209. Baltimore: Johns Hopkins University Press, 2002, p154.

¹²⁴ Oregon Public Health Division, Annual Reports under the Death with Dignity Act: for the most recent report see <http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year18.pdf>

¹²⁵ Secretariat of Pro-Life Activities, "Assisted Suicide Laws in Oregon and Washington: What Safeguards", Washington D.C., 2015.

4.6.4 Doctor shopping

Foley and Hendin explore a case study in Oregon involving a woman in her mid-eighties with metastatic breast cancer who was in a hospice program. Given the lack of transparency surrounding assisted dying in Oregon, the information that they gathered included: reports from the staff of Compassion in Dying (the organisation that facilitated the assisted death); a news conference following the death; and information from anonymous interviews by the physician who prescribed the medication. According to these sources, the patient's *own* physician was not willing to assist in her suicide (for reasons not specified), a second physician refused on the basis that the patient was depressed and it was only when Compassion in Dying was contacted that a doctor was found who was willing to prescribe a lethal medication. The patient was seen by a psychiatrist – but only once.¹²⁶

While legally proscribed procedures appear to have been followed, the case raises a number of questions. First, the views of the patient's own doctor and the physician who believed that she was suffering from depression were essentially ignored. All that was required was for the patient to find another doctor willing to undertake the procedure. Any regime that permits such doctor shopping is prone to abuse. This kind of outcome is possible in a number of the euthanasia and assisted dying regimes currently in place.

This is similar to what occurred in the case of Godelieva De Troyer and is reflected in a study in Belgium which found that in 23 per cent of cases, euthanasia was preformed despite a divergence of opinions.¹²⁷

4.6.5 Nurses administering medicine

Recent studies provide evidence that in Belgium nurses commonly administer fatal doses in contravention of the law. One recent study surveyed 6,000 nurses in Flanders. Of 1,265 completed surveys, 128 nurses reported that the last patient in their care for whom a life-shortening end-of-life decision was made received euthanasia and 120 reported that the patient received life-ending drugs without his or her explicit request. Of the nurses involved in euthanasia, 64% were involved in the decision-making process. The drugs were administered by the nurse in 12% of cases, mostly without the physician co-administering (12/14 = 86%).¹²⁸ In using life-ending drugs without explicit request, 48% of nurses helped prepare drugs, 56% were present during administering and in 45 instances, the nurse administered the drugs, mostly without the physician co-administering (82%) but under physician orders (98%).¹²⁹

¹²⁶ Foley K and Hendin H (Eds.) *The Case against Assisted Suicide, For the Right to End-of-Life Care*. Pp192-209. Baltimore: Johns Hopkins University Press, 2002, pp146-148.

¹²⁷ Cohen-Almagor, "First do no harm: pressing concerns regarding euthanasia in Belgium", *International Journal of Law and Psychiatry*, 36 (2013): 515-521.

¹²⁸ E. Inghelbrecht, J. Bilsen, F. Mortier, L. Deliens, "The role of nurses in physician-assisted deaths in Belgium", *Canadian Medical Association Journal*, 182 (9) (2010, June 15), p 907.

¹²⁹ E. Inghelbrecht, J. Bilsen, F. Mortier, L. Deliens, "The role of nurses in physician-assisted deaths in Belgium", *Canadian Medical Association Journal*, 182 (9) (2010, June 15), pp 905-910.

Another study focused on situations in which patients were euthanised without having made an explicit request to die. This study found that, in almost half of the cases (6 of 13), the final drug was administered by a nurse.¹³⁰

The administration of drugs by nurses is not a major concern per se. Nurses are often the key caregivers at the end of life with the most intimate knowledge of a patient's preferences and needs. What is relevant in the current context is the fact that this practice is prevalent in a situation that is highly sensitive (the administration of fatal doses) and where the law clearly states that it should not occur. Clearly, in regimes where euthanasia and assisted suicide are legal, practices that breach the law occur and the extent to which they occur is not clear.

4.6.6 Potential conflicts of interest in supervisory body membership

Some of the physicians involved in recently high profile, controversial cases in Belgium sit on the Federal Control and Evaluation Commission, raising questions about the sufficiency of procedures to ensure the independence of the key regulatory body.¹³¹

4.6.7 Very few officially reported procedural failures

The number of reported procedural failures calls into question the effectiveness of current controls.

In Belgium, as of 2015, the Federal Control and Assessment Commission had only referred a single case of euthanasia to the Crown Prosecution Service out of more than 9,400 cases reported.¹³² In the Netherlands, out of 4,178 cases of euthanasia in 2012, 10 were found to be non-compliant and of 5,512 cases in 2015, 4 were found to be non-compliant.¹³³

A near zero non-compliance rate stretches credulity given the well documented cases above of:

- the existence of widespread practices in the grey area of what is legal, even in countries with legalised euthanasia/assisted suicide, including: publicly reported cases involving deaths that stretch the bounds of the law; and practices involving the use of life-ending drugs without explicit patient request;
- growing numbers of people undergoing euthanasia with mental illness and/or depression;
- regulatory agencies openly conceding their own limitations in monitoring the actual number of instances of euthanasia;
- doctors not reporting cases to the central authorities; and
- other procedural irregularities.

¹³⁰ K. Meeussen, L. Van den Block, N. Bossuyt *et al.*, "Physician reports of medication use with explicit intention of hastening the end of life in the absence of explicit patient request in general practice in Belgium", *BMC Public Health*, 10 (2010), p. 186.

¹³¹ Lemmens, Trudo, *The Conflict Between Open-ended Access to Physician-Assisted Dying and The Protection of the Vulnerable: Lessons from Belgium's Euthanasia Regime in the Post-Carter Era*, (forthcoming), Catherine Regis, Lara Khoury & Robert Kouri, eds., *Key Conflicts in Health Law*, (Cowensville: Yvon Blais, 2016), pp25-26.

¹³² Lemmens, Trudo, *The Conflict Between Open-ended Access to Physician-Assisted Dying and The Protection of the Vulnerable: Lessons from Belgium's Euthanasia Regime in the Post-Carter Era*, (forthcoming), Catherine Regis, Lara Khoury & Robert Kouri, eds., *Key Conflicts in Health Law*, (Cowensville: Yvon Blais, 2016), p24.

¹³³ Dutch Regional Euthanasia Committees, see 2014 and 2015 reports.

4.6.8 Failure of drugs performing as designed

In Oregon, according to official statistics 24 patients are known to have regurgitated some of the legal dose and six regained consciousness after taking the drugs and died later.¹³⁴

In Washington State, according to official statistics, there have been at least 8 cases of regurgitation, 2 cases of “other” complications (2012 and 2015) and a seizure (2014).¹³⁵

A study of euthanasia and assisted suicide in the Netherlands found that complications arose in 7 per cent cases of assisted suicide and problems with completion (such as a longer-than-expected time to death, failure to induce coma or induction of coma following the awakening of the patient) occurred in 16 per cent of cases. The rate of complications and completion were lower in the case of euthanasia (3 per cent and 6 per cent respectively).¹³⁶

The proportion of complications is likely to be higher in assisted suicide schemes (such as that proposed in the Majority Report) than with euthanasia as it will generally be more difficult to ensure appropriate supervision of the administration of the lethal dosage in cases of assisted suicide.

Box 3: Failure of Safeguards

The following safeguards have proved to be difficult to enforce:

- **Reporting:** in Belgium, half or more cases of euthanasia are not reported to the FCEC. This is also a problem in the Netherlands.
- **Patients with depression:** suffering from depression does not mean that a person lacks competence to make important decisions, including whether to opt for euthanasia or assisted suicide. However, it is well documented that serious depression can impact on decision-making, which makes it an area of particular concern given the irreversibility of a decision to hasten one’s death. In addition, the categorisation of some forms of depression as treatment-resistant is problematic as numerous studies have indicated that, in at least some instances, such conditions can be managed.
- **Mentally ill patients:** the number of patients with mental illness being granted access to euthanasia and assisted suicide is increasing rapidly. There is considerable evidence of situations in which properly trained psychiatrists are not being adequately consulted.
- **Coercion:** it is well documented that people who are terminally ill often feel as though they are a burden on their family or carers. This can result in a subtle indirect coercion or, in some instances, a more overt coercion to actively consider a hastening of death.
- **Independent consultations:** in all jurisdictions, there is either a lack of transparency or at least some evidence that independent reviews are not occurring in some cases.

¹³⁴ For the number of regurgitations, see Table 1 of the 2015 report:

<http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year18.pdf>

For the number of instances of regained consciousness see Table 1 of the 2015 report but also, for more detailed breakdown, see Oregon Public Health Division Report for 2012, Table 1, note 13.

<http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year16.pdf>

¹³⁵ Washington State Department of Health, *Washington State Department of Health 2015 Death with Dignity Act Report*, see reports for the years 2011-2015.

See <http://www.doh.wa.gov/portals/1/Documents/Pubs/422-109-DeathWithDignityAct2015.pdf> and reports for 2012-2014

(Accessed 30 May 2016)

¹³⁶ Groenewoud, Johanna, Agnes van der Heide, Bregje D. Onwuteaka-Philipsen, Dick Willems, Paul van der Maas and Gerrit van der Wal, “Clinical Problems with the Performance of Euthanasia and Physician-Assisted Suicide in the Netherlands”, *New England Journal of Medicine*, 2000, 342, 551-556.

4.7 Failure to monitor what occurs outside the law

It is true that many practices in Victoria at present operate outside the full view of the law. But to suggest that all activities undertaken at death are transparently monitored in regimes with legal euthanasia or assisted suicide is clearly not correct.

If anything, it is possible that a normalisation of the hastening of death might create an environment in which even more dubious activity occurs in the grey area that is known to exist but not actively monitored by law enforcement agencies or health regulators.

As noted above, in Belgium, the FCEC has conceded that it has little power to investigate what occurs beyond the reports that it receives from physicians. This is true to varying degrees in all jurisdictions.

Chin et al note that the Oregon Health Division is charged with collecting data under the Dying with Dignity Act and to report cases of noncompliance to the Oregon Board of Medical Examiners. However, they also note that:

Our responsibility to report noncompliance makes it difficult, if not impossible, to detect accurately and comment on underreporting. Furthermore, the reporting requirements can only ensure that the process for obtaining lethal medications complies with the law. We cannot determine whether physician-assisted suicide is being practiced outside the framework of the Death with Dignity Act.¹³⁷

These examples are corroborated by expert evidence to the Canadian Supreme Court. Professor Etienne Montero was retained by the Attorney-General of Canada to provide impartial, expert opinion to the Supreme Court of Canada in the case of *Carter v the Attorney-General of Canada et al.*¹³⁸ When commenting on the Belgian regime, his analysis led him to conclude that:

the provisions of the Act, as seemingly strict as they are, cannot be strictly enforced and controlled ...¹³⁹

¹³⁷ Chin, Arthur, Katrina Hedberg, Grant Higginson and David Fleming, "Legalized Physician-Assisted Suicide in Oregon – The First Year's Experience", *New England Journal of Medicine*, 1999, 340: 577-583.

¹³⁸ Montero, Professor Etienne, Affidavit to Lee Carter v The Attorney General of Canada et al, Supreme Court of Canada, No. 35591, pp39-63.

¹³⁹ Montero, Professor Etienne, Affidavit to Lee Carter v The Attorney General of Canada et al, Supreme Court of Canada, No. 35591, p41.

Box 4: Legalisation simply shifts where hidden activities occur

The argument that a legalized system creates transparency and ensures a clear understanding of what is happening in real life thus needs to be qualified: it gives us more data, but hidden practices remain and interpretation of the reported cases of compliance and non-compliance call for further refinement and interpretation. Although impossible to obtain reliable evidence, it could very well be that there is simply a data shift, with previously hidden practices now regulated, and an increase of other forms of euthanasia, including involuntary euthanasia and practices that do not respect the legal procedures. The *post-factum* reporting systems of Belgium and the Netherlands neither prevent this nor provide us more certainty about what is indeed happening. They could just as easily give us a false sense of security and control over the practice.¹⁴⁰

4.8 Noteworthy individual cases

This paper has largely focused on broader, peer-reviewed quantitative studies. This section will highlight some individual cases that relate to concerning trends in the current practice of euthanasia and assisted suicide in some jurisdictions. While focusing on individual cases can be criticised as resorting to anecdote, these cases usefully supplement the studies cited above.

Advocates of euthanasia often cite individual cases so as to stress the human consequences of the restrictions contained in current laws. That is appropriate. It is equally appropriate to stress the human side of the negative consequences of regimes that aim to help a certain group of people but inadvertently result in harm and abuse more broadly.

The following are a small number of the many problematic cases that have made it into the public sphere. It is likely that many more escape public attention:

- **Psychiatric patients:** the euthanasia of a psychiatric inmate in Belgium who was, at the time, incarcerated. Dr Marc Moens, President of the Association of Belge des Syndicats Medicaux (ABSyM) noted that: “Even if the request for euthanasia meets all the statutory conditions, the burning question in this social debate is whether the inmate would have made this decision under the appropriate psychiatric treatment.”¹⁴¹
- **Transgender:** the euthanasia of Nathan Verhelst (born Nancy) after at 44, after an unsuccessful sex change operation has raised questions about whether more support could have alleviated the distress experienced after the operation.¹⁴²

¹⁴⁰ Lemmens, Trudo, *The Conflict Between Open-ended Access to Physician-Assisted Dying and The Protection of the Vulnerable: Lessons from Belgium’s Euthanasia Regime in the Post-Carter Era*, (forthcoming), Catherine Regis, Lara Khoury & Robert Kouri, eds., *Key Conflicts in Health Law*, (Cowensville: Yvon Blais, 2016), p32.

¹⁴¹ Moens, Dr Marc, president of the ABSyM, press release [translation] *Psychiatric inmates have the right to medical care* (13 September 2012), and see referred to in Montero, Professor Etienne, *Affidavit to Lee Carter v The Attorney General of Canada et al*, Supreme Court of Canada, No. 35591, p44.

¹⁴² *La Libre Belgique* (October 1, 2013) and also reference in Lemmens article, pp50-51.

- **Anticipation of future pain or suffering:** there are a number of instances of people being euthanised as a result of their anticipation of future pain, including Hugo Clause (renowned Flemish author); Christian de Duve (Nobel Prize in Medicine 1974); Emiel Pauwels and others.¹⁴³
- **Anticipation of blindness:** another high profile case was the euthanasia of twins Eddy and Marc Verbessen who were born deaf and were euthanised together at age 45 on the basis of a diagnosis of glaucoma which was gradually making them blind.¹⁴⁴
- **Tinnitus:** a 47-year old woman in the Netherlands was euthanised for tinnitus that was deemed to be incurable.¹⁴⁵
- **Depression:** there are many high profile cases where arguably treatable depression was the cause of the euthanasia, including the highly publicised case of Godelieva De Troyer as reported in *the New Yorker*.¹⁴⁶ In Oregon, the case of Michael Freeland received public attention as he consented to the release of his records. Over a year after receiving his prescription, Mr Freeland was admitted to a psychiatric facility with depression and suicidal intent. His treating psychiatrist wrote a letter to the court the day after his discharge saying he was not competent and needed a guardian. Mr Freeland accidentally called Physicians for Compassionate Care (he was trying to contact the suicide advocacy organisation Compassion in Dying) and was treated for his depression and assisted in reconciling with his estranged daughter. Several weeks later he died naturally and comfortably without taking lethal drugs - some two years after receiving his first lethal dose prescription.¹⁴⁷
- **Multiple disorders:** the case of Jeanne is illustrative. Jeanne was 88 years old and suffered from multiple conditions that cumulatively caused unbearable pain but that were not individually sufficient to justify euthanasia. For her former attending physician, it was “obvious that she did not have a serious incurable disease as required under the Act”.¹⁴⁸ The number of cases of “multiple disorders” increased from 3 in the FCEC’s first report to 57 in the fifth report.¹⁴⁹
- **Old age:** the case of Amelie Van Esbeen gained considerable publicity as it appeared that her old age was the principal reason for her being euthanised. Of note was that her attending physician refused to grant her request.
- **Doctor shopping:** The case of Kate Cheney in Oregon outlined above in detail is a good example of doctor shopping. The opinions of more than one doctor were essentially ignored.¹⁵⁰ Another instance of doctor shopping in Oregon involved a patient of Dr Charles Bentz, who would not prescribe a lethal dosage as the patient had documented depression for which he needed treatment. The patient’s oncologist found another physician required to provide the “second opinion” and did not refer the patient back to his primary physician at all. Dr Bentz obtained

¹⁴³ Montero op cit pp 45-45 and see also discussion in Lemmens, op cit, pp51-52 in relation to the elderly couple Anne and Francois, who were suffering from significant medical issues but were not at immediate risk of dying. They requested a desire to be euthanised together to avoid the prospect of being alone should one survive the other.

¹⁴⁴ Montero op cit pp 45-45 and also discussion in Lemmens, op cit, pp49-50.

¹⁴⁵ See this reported in the Guardian: <http://www.theguardian.com/lifeandstyle/2015/sep/11/assisted-dying-dutch-end-of-life-netherlands-unbearable-suffering>

¹⁴⁶ Avid, Rachel, “The Death Treatment”, *The New Yorker*, June 22 2015.

See: <http://www.newyorker.com/magazine/2015/06/22/the-death-treatment>

¹⁴⁷ See information provided by Vermont Alliance for Ethical Health Care, www.vaeh.org.

See also: <http://www.pccf.org/articles/art60.htm>

¹⁴⁸ Montero, Professor Etienne, Affidavit to Lee Carter v The Attorney General of Canada et al, Supreme Court of Canada, No. 35591, p46.

¹⁴⁹ Montero, Professor Etienne, Affidavit to Lee Carter v The Attorney General of Canada et al, Supreme Court of Canada, No. 35591, p49.

¹⁵⁰ Foley K and Hendin H (Eds.) *The Case against Assisted Suicide, For the Right to End-of-Life Care*. Pp192-209. Baltimore: Johns Hopkins University Press, 2002, pp156-157. See also information provided by Vermont Alliance for Ethical Health Care at www.vaeh.org.

permission from the patient's family and obtained a copy of the death certificate which stated that death was from malignant melanoma.¹⁵¹

- **Feeling like a burden:** The case of Kate Cheney is an example of the potential impact of pressure due to feeling like a burden on one's family.¹⁵²
- **Difficulty in diagnosis:** In Oregon, Barbara Houck, aged 71, was diagnosed with Amyotrophic Lateral Sclerosis. She met with Dr Peter Rasmussen, an oncologist (but not a neurologist) and supporter of physician-assisted dying. Dr Rasmussen declined to give the prescription because he judged that she had more than 6 months to live. She saw him again in March and he gave the prescription. This case raises difficulties about the suitability of an oncologist giving an evaluation and prognosis for an uncommon neurologic disease.¹⁵³ Another case involved a cancer patient, Jeanette Hall. A doctor had given her a terminal diagnosis of six months to a year to live, based upon not being treated for the cancer. She was referred to Dr Kenneth Stevens. On her first visit with Dr Stevens she made it clear that she did not want to be treated. After suggesting that she discuss the idea with her son, she agreed to treatment and, at the time of Dr Stevens' affidavit, had been alive for 13 years. In his view, "the mere presence of legal assisted suicide had steered her to suicide."¹⁵⁴

4.9 Conclusion

This chapter has explored various reasons why it is likely that the number of instances of euthanasia and assisted dying continue to grow so strongly, even after a period of almost two decades following legalisation in some jurisdictions.

The most plausible explanations for the growth in overall numbers are:

- An increase in the scope of regimes, whether by legislative amendment or the reinterpretation of existing legislative provisions.
- A normalisation of the decision to opt for euthanasia or assisted suicide.
- An increase in the number of cases of euthanasia of people in a vulnerable position.
- A failure of safeguards to limit the operation of schemes within the boundaries originally intended.

The evidence of Professor Etienne Montero to the Canadian Supreme Court summarises the risks that legalisation would expose Victoria to:

legislative openness to euthanasia inevitably leads to certain abuses and excesses, to a violation of the letter and the spirit of the law, and to a broadening of the scope of the Act beyond the borders initially and firmly established.¹⁵⁵

¹⁵¹ Vermont Alliance for Ethical Health Care at www.vaeh.org.

¹⁵² Foley K and Hendin H (Eds.) *The Case against Assisted Suicide, For the Right to End-of-Life Care*. Pp192-209. Baltimore: Johns Hopkins University Press, 2002, pp156-157. See also information provided by Vermont Alliance for Ethical Health Care at www.vaeh.org.

¹⁵³ Vermont Alliance for Ethical Health Care, www.vaeh.org.

¹⁵⁴ Stevens, Dr Kenneth R., Affidavit in *Montanans Against Assisted Suicide & For Living With Dignity vs Board of Medical Examiners*, Montana Department of Labour and Industry, sworn at Craig D. Charlton Charlton Law Firm, 16 October 2013.

¹⁵⁵ Montero, Professor Etienne, Affidavit to *Lee Carter v The Attorney General of Canada et al*, Supreme Court of Canada, No. 35591, p41.

CHAPTER 5 – ISSUES WITH THE PROPOSED REGIME

The proposed regime for assisted dying contains a number of elements that have proved highly problematic in jurisdictions with legalised euthanasia or assisted suicide. While the scheme set out in the Majority Report claims that it contains a number of safeguards, there is serious doubt as to whether these will be effective in practice.

These include:

- **Scope creep.** Given what has occurred in other jurisdictions, the potential for any entity that is established to expand the scope an assisted suicide regime in Victoria through non-transparent reinterpretations of legislative provisions should not be discounted.
- **Independent review.** The proposed regime would do little to prevent doctor shopping, a practice that is widespread in other jurisdictions. This calls into doubt the effectiveness of the requirement for independent appraisals.
- **Post-factum reporting.** This approach to reviewing cases has proved to be ineffective in a number of jurisdictions, with low rates of reporting and transparency in Belgium and the Netherlands.
- **A requirement that patients have a terminal condition.** As is noted above, this is extremely difficult to enforce in practice, with doctors often disagreeing on whether a condition is terminal. This will be exacerbated by the fact that the requirement will not contain a specific time limit. Even in jurisdictions with a time limit, it has been difficult to enforce this condition.
- **That physicians will be able to administer drugs in certain circumstances.** This is a significant expansion from some assisted suicide regimes. Given that many aspects of regulatory environments have expanded in scope through interpretation, this could become a major loophole.
- **Psychiatric evaluations.** The proposed regime does little to deal with the growing problem of how to diagnose and treat depression and mental illness and, in addition, how to interpret and manage the impact of such conditions on consent.

CHAPTER 6 – ISSUES WITH POLLING RESULTS

It is often claimed that a strong majority in the community support euthanasia or assisted dying. It is true that a number of polls have been undertaken over the past two decades and that somewhere between 65 and 80 per cent of those polled have indicated support for euthanasia.

Given the limitations of some polls to date, it would be worthwhile examining public sentiment in a more detailed, rigorous manner.

6.1 Issues that warrant further examination

There are a number of methodological issues with of the polls that are cited by euthanasia advocates:

- The question is sometimes put in a confusing or ambiguous manner. For example, terms like “dying with dignity” and “assisted dying” could mean different things to different people. Some people consider the use of high doses of pain relief, even if it might have negative consequences, as “assisted dying” – yet this is clearly legal at present and considered part of standard practice by the medical profession.
- At least some of the polls suffer from “framing” issues. It is well established that the way a question is framed can affect the results. In the case of euthanasia and assisted dying, support for legalisation could potentially be affected by references to whether safeguards are seen as appropriate and whether the person being polled would be concerned if was established that safeguards are not working in at least some jurisdictions.

A more rigorous approach would be to undertake layered questioning that disentangles questions such as withdrawal of treatment, the application of pain relief (even if it might hasten death) and euthanasia/assisted suicide.

It would also be worthwhile undertaking polling with groups who have been informed about current best practice palliative care options. It is well established that providing balanced information to people prior to polling can have a material impact on results.

6.2 Specific wording of recent questions

It is worth focusing on some of the specific questions that have been asked in recent polls.

Ambiguous wording

In 2014, the ABC Vote Compass found 76 per cent support for the following proposition:

*Terminally ill patients should be able to legally end their own lives with medical assistance*¹⁵⁶

¹⁵⁶ <http://www.abc.net.au/news/2014-11-23/victorians-back-voluntary-euthanasia-vote-compass/5910668>

This is a good example of a question that is arguably ambiguous. The phrase "... with medical assistance" could mean the administration of high dosages of pain relief in the eyes of many – a practice that is currently permitted under the law. It is important to be clearer than this proposition.

Support for tightly defined entitlement

Where there is support for a clearly defined proposition, it is almost always confined to people who are terminally ill and experiencing unendurable suffering.

In 2015, there was 72 per cent support for assisted suicide in a poll commissioned by Essential Media Communications. The question was:

Q. When a person has a disease that cannot be cured and is living in severe pain, do you think doctors should or should not be allowed by law to assist the patient to commit suicide if the patient requests it?¹⁵⁷

This question includes the phrases "cannot be cured" and "living in severe pain".

In a 2012 Newspann, over 80 per cent supported the following euthanasia in the following situation:

hopelessly ill patient, experiencing unrelievable suffering, with absolutely no chance of recovering

As is discussed in detail above, many people currently opting for assisted suicide in North America and euthanasia and assisted suicide in Europe are not in severe pain at the time of the request. Moreover, in assisted dying regimes of the type supported by the Majority Report, there is little evidence that lethal doses are necessarily only given at such times.

It would be worth testing support for the proposition if it was in a broader context. In particular, it would be worthwhile testing community support for assisted suicide and euthanasia in situations not involving unendurable physical pain, such as anticipation of pain, loss of hope etc, which routinely give rise to assisted suicide in jurisdictions where it is legal.

6.3 The need for layered polling

It would be worthwhile testing framing effects. For example, is public support for assisted suicide or euthanasia contingent on the effectiveness of safeguards? Does the level of support change if people are aware of the rapid growth in the number of cases of assisted suicide and euthanasia in all jurisdictions where it is legal and the large body evidence calling into doubt the effectiveness of safeguards?

In polling undertaken by Environics Research Group, a majority of Canadians either strongly support (21%) or somewhat support (36%) legalising euthanasia. This is considerably higher than the proportion who strongly oppose (20%) or somewhat oppose (8%).¹⁵⁸

¹⁵⁷ <http://www.essentialvision.com.au/voluntary-euthanasia-3>

In the same survey:

- almost two thirds of those surveyed expressed concern that elderly Canadians could be pressured into accepting euthanasia (66% concerned vs 33% not concerned).¹⁵⁹
- almost eight in ten express concern that a significant number of sick, disabled or elderly could be euthanised without their consent (78% concerned vs 20% not concerned).¹⁶⁰

These are not mutually inconsistent positions. But it suggests that, at least to some degree, support for the legalisation of euthanasia and assisted suicide is contingent on the implementation and maintenance of effective safeguards. It is worth exploring how an informed, evidence-based discussion about these concerns could affect support levels.

Abingdon Research undertook a poll of attitudes to euthanasia in Quebec. 74% of respondents either strongly or moderately supported the legalisation of euthanasia.

The people surveyed were then asked to respond to six potential scenarios each dealing with risks associated with the reform. A significant proportion expressed concerns in relation to these risks. After being exposed to these concerns, 47% indicated that they felt the subject required further study, while 35% continued to advocate for legalisation.¹⁶¹

It would be worthwhile exploring the relationship between the risks associated with potential reform and the level of support for legalisation.

¹⁵⁸ Environics Research Group, *Canadians' Attitudes Towards Euthanasia*, Commissioned Research for Life Canada, October 2010, p5.

¹⁵⁹ Environics Research Group, *Canadians' Attitudes Towards Euthanasia*, Commissioned Research for Life Canada, October 2010, p11.

¹⁶⁰ Environics Research Group, *Canadians' Attitudes Towards Euthanasia*, Commissioned Research for Life Canada, October 2010, p14.

¹⁶¹ Abingdon Research, Quebec "Medical Aid in Dying Survey", 2013, p25.

RECOMMENDATIONS

RECOMMENDATION 1: That the Victorian government undertake rigorous analysis of trends in euthanasia and assisted suicide in foreign jurisdictions before deciding whether to develop a legal regime for consideration. This would include an understanding of:

- best practice palliative care in Victoria, Australia and internationally.
- the prevalence of failure in safeguards in euthanasia and assisted suicide regimes.
- the extent to which illegal activity continues to occur in jurisdictions with legal euthanasia or assisted suicide.
- the extent to which a rising number of instances of euthanasia or assisted suicide is impacting on the overall health care system.

RECOMMENDATION 2: That rigorous, layered polling be undertaken in Victoria and that this polling:

- clearly set out the scope of the reform being tested.
- adopt a range of different “frames” for the question, including frames that indicate the risks associated with containing the scope of euthanasia or assisted suicide in practice.
- explore the relationship between a person’s awareness of and attitude towards the various risks associated with legalisation and their level of support for legalisation.

CONCLUSION

The legalisation of either assisted suicide or euthanasia would represent a fundamental shift in the regulation of medical practice in Victoria. Overseas experience over almost two decades suggests that, while such a change may benefit a small minority of people toward the end of life, many more may be worse off as a result.

This Minority Report has argued that:

- It is possible to respect individual autonomy while not empowering health professionals to actively participate in acts of assisted suicide or euthanasia.
- Even if it can be argued that euthanasia or assisted suicide are justifiable in some instances, the negative consequences arising from legalisation far outweigh the benefits arising in that minority of cases.

In only a very small minority of end-of-life situations are the symptoms of pain unmanageable

Experts in palliative care, oncology and related fields provided the Committee with powerful evidence that almost all symptoms arising from physical pain at the end of life can now be managed. The palliative care and oncology experts who gave evidence also stated that, over long careers, the number of people expressing a desire to have their life shortened was very small. Moreover, pain relief techniques and palliative care are constantly improving.

Even where there is an expressed desire to die, it is critically important to understand the nuances of such requests. Where the person making the request is experiencing depression or a mental illness, which is relatively common, there are usually treatment options worth exploring. Holistic palliative care and other forms of assistance can often provide effective relief, even if not complete, and can often lead to a reversal in the expressed desire.

Consideration of assisted suicide and euthanasia requires a consideration of more than how best to give effect to individual autonomy

Proper consideration of assisted suicide and euthanasia requires an evaluation of the likely broader social impacts of the reform in addition to issues relating to individual autonomy. Individual autonomy is of great importance, but it is not the only consideration.

While there is arguably a gain from giving effect to some patients' wishes to hasten their death, this must be weighed against the potential for societal harm through a range of potential negative consequences, including: vulnerable people being pressured into euthanasia or assisted suicide; people having their death hastened without having given proper consent; and a gradual broadening of practices without transparent public consideration.

In practice, euthanasia and assisted suicide are a disproportionate response that cause far more social harm than good

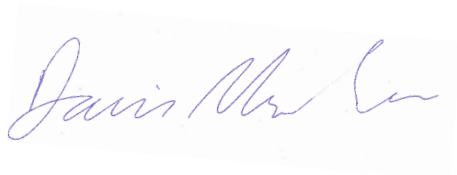
The evidence is clear that the number of instances of euthanasia and assisted suicide is growing rapidly in all major jurisdictions where it is legal. This has been occurring for almost two decades in some jurisdictions, with no sign of abatement.

The usage of euthanasia and assisted suicide in practice is far out of proportion to the situations that were originally used to justify the practice in these jurisdictions: namely, that small minority of cases where the symptoms of pain are unmanageable. Moreover, the rapid growth in documented cases of euthanasia and assisted suicide probably materially understates the actual prevalence of the practice given low rates of reporting.

The effectiveness of safeguards in jurisdictions with legalised assisted suicide and euthanasia has been called into question by many academic studies and high profile media investigations. This, coupled with the growing prevalence of the practice, is a matter of great concern.

While legalisation was supposed to bring what was occurring in the shadows into the light, legalisation has simply pushed the boundary of what is legal out further and may have increased the amount of activity that occurs beyond the sight of regulators. Evidence suggests that it is doubtful that safeguards are working as intended, particularly for vulnerable people.

It is very unfortunate that some symptoms of pain cannot be totally managed – but the legalisation euthanasia or assisted suicide is not the appropriate response.



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