

Written evidence submitted by The BIOS Centre (ADY0417)

What happens when euthanasia and assisted suicide become public policy?

Bios Centre

The Bios Centre is a bioethics institute which carries out research across various disciplines for the benefit of health care professionals and others interested in good and equitable healthcare practice. Our researchers include practising medical doctors and medical researchers, bioethicists and legal scholars. We are responding to this consultation as it engages our research interests in end-of-life care and in euthanasia and assisted suicide and the societal effects of their legalisation.

Summary

- *In this Submission, we respond to the Consultation's question concerning the practice of euthanasia/assisted suicide in countries where these practices are legal.*
- *The 'hard case' standardly presented to legislators and the public, involving unbearable pain for a terminally ill adult who makes a free, informed and persistent request overseen by the authorities, and with safeguards against coercion and abuse, is not reliably how assisted dying comes to be practised.*
- *Pain or concern about pain – in contrast to loss of ability – is not the main reason for seeking euthanasia/assisted suicide in Canada or Oregon, for example.*
- *Assisted dying for mental suffering raises particular problems since mental illness is often poorly understood, recovery from depression is difficult to predict, and treatments vary in efficacy and availability. Nonetheless, cases of psychiatric euthanasia have steadily risen in Belgium and the Netherlands.*
- *There is also a troubling incidence of requests for assisted dying from those who perceive themselves to be a burden to others. The offer of euthanasia to disabled people sends a message that encourages despair on the part of those needing social support.*
- *As regards consent in any form, non-voluntary euthanasia of infants, children and adults with mental incapacity is a reality in Belgium and the Netherlands.*
- *The evidence is that the different values – autonomy and the presumed benefit of death – that undergird euthanasia and assisted suicide for hard cases contain within them the seeds of expansion well beyond those cases. Therefore, the hard cases cannot be legislated for without taking these other problematic cases into account.*

Introduction

As we see it, there are many reasons for opposing legal euthanasia and assisted suicide, but perhaps the most urgent reason is that neither can be confined to the hard cases which are used to justify their practice.¹ The archetypal hard case is usually thought of as one where there is unbearable physical pain for someone terminally ill or close to death and in which nothing can be done to

¹ See references in the text below and also Keown J. (2018). *Euthanasia, ethics and public policy: an argument against legalisation*. Cambridge University Press, Cambridge; Jones DA et al. Eds. (2018). *Euthanasia and assisted suicide: Lessons from Belgium*. Cambridge University Press, Cambridge; Pike G (2020). *Euthanasia and Assisted Suicide: When Choice is an Illusion and Informed Consent Fails*, <https://bioscentre.org/articles/euthanasia-and-assisted-suicide-when-choice-is-an-illusion-and-informed-consent-fails/> Accessed 18 January 2023.

alleviate their suffering. The person must, it is assumed, be an adult, make a free, informed and persistent request, be conscious and have capacity at the time of the lethal dose. The decision must be overseen with careful judgement by medical authorities. There must be high quality reporting and safeguards against coercion, elder abuse, and abuse of disabled persons. It is this kind of conception of euthanasia and assisted suicide which is put to the public and voted on by decision-makers.

However, as we will demonstrate in this submission, there is extensive evidence to show that, in practice, such a conception is impossible to realise. Therefore, any changes to the law appealing to this type of hard case will only serve to mislead the public, damage trust in policymakers, and provide some individuals with control over their deaths at the expense of the lives of many other vulnerable people in society who will no longer be protected by the law. A prudent, detailed analysis of the available evidence shows that assisted dying (assisted suicide and/or euthanasia) policies soon morph into something very different from what was originally intended, encompassing wider categories of persons and wider interpretations of suffering, and placing the frail and vulnerable at risk of death.

In each of the following sections we consider what has happened over time regarding the initially mandated requirements, revealing an ever-expanding practice of assisted suicide and euthanasia. If, as we contend, there is a certain inevitability about those changes, then that is critical information for both the public and decision makers concerning the reality of the path they are considering embarking upon. Most of what follows reveals expansion from assisted dying after a voluntary choice to assisted dying either without choice or where choice is compromised.

Legalising euthanasia and/or assisted suicide is chiefly argued for on two grounds, often in combination. The first is the primacy of autonomy and the second is that death is a benefit (to avoid suffering). Once these are accepted in principle, the limits of either are open for expansion as restraint is eased. If autonomous choice is emphasised then it should not be surprising that the practice of euthanasia/assisted suicide expands to include suffering that is psychological rather than physical, or even existential as in 'tired of life' cases.² If death is conceived as a benefit and a medical solution to suffering then it is not surprising that euthanasia naturally expands to include minors and infants and adults with mental incapacity, even those who made no previous request. It is very problematic to legislate for effective restraints on the expansion of lawful termination of life, since the 'autonomy' and 'benefit' justifications for the classic hard cases of euthanasia and assisted suicide are intrinsically vulnerable to such expansion (see below).

A foundational role of the State is to protect the lives of its members, especially the vulnerable. This is exemplified by the central place that the 'right to life' enjoys in various articles of the international human rights instruments – a right which the European Court of Human Rights recognised as in no way conferring a 'right to die'.³ The right to life is undermined if the State enables some of its members – the medical profession – to terminate (or help to terminate) the lives of other of its members. This would be a failure of the State's duty of protection and would leave the door open to other social and legislative changes by which members' lives can be placed at risk of death. Each of

² A society which endorses someone's decision that it is legitimate, rational and acceptable intentionally to end life, even when there is no more compelling reason than being 'tired of life', is a society which will see the early exit of the weak and frail. Disturbingly, there may even be some who see this as a solution to the cost of caring for certain less favoured groups in an aging population.

³ The Court of Strasbourg in the Case of Pretty v the UK (app. n. 2346/02) says on art. 2 ECHR (right to life) - which is an absolute right - "39. Article 2 cannot, without a distortion of language, be interpreted as conferring the diametrically opposite right, namely a right to die; nor can it create a right to self-determination in the sense of conferring on an individual the entitlement to choose death rather than life.

40. The Court accordingly finds that no right to die, whether at the hands of a third person or with the assistance of a public authority, can be derived from Article 2 of the Convention."

See also the Equality and Human Rights Commission overview on art. 2 (ECHR),

<https://www.equalityhumanrights.com/en/human-rights-act/article-2-right-life> Accessed 17 January 2023.

the following sections will detail the various ways that assisted dying regimes increase this risk and their failure to operate as originally intended.

Reasons given for Euthanasia/Assisted Suicide: Loss of Autonomy/Ability/Dignity; Burdensomeness; Physical Pain

In the most recent report from Canada, the main two reasons for choosing euthanasia referred not to physical pain but to “Loss of ability to engage in meaningful activities” (84.9%) and “Loss of ability to perform activities of daily living” (81.7%).⁴ Reference to pain was difficult to unravel because the chosen wording was “Inadequate control of pain (or concern)”, cited in 57.4% of cases. Note that this figure is not restricted to those experiencing severe pain since there is no means of knowing the severity of the inadequately controlled pain and, further, it encompasses those who are merely concerned about what pain they may suffer in the future. This also raises questions about access to, and information about, good palliative care, bearing in mind that the option of deep sedation does exist for pain that is otherwise difficult to control.

In Oregon in 2020, the main four reasons cited by those who received assisted suicide were “less able to engage in activities making life enjoyable” (94.3%); “losing autonomy” (93.1%), “loss of dignity” (71.8%) and “burden on family, friends/caregivers” (53.1%). “Inadequate pain control, or concern about it” was cited by 32.7%.⁵

The Australian Northern Territory had a brief experiment with euthanasia in the nineties with its *Rights of the Terminally Ill Act, 1995* (ROTTI). Seven people accessed the law and four were eventually euthanised under the Act.

Key findings were that those involved experienced social isolation and depression, and there was a lack of consensus about whether their illnesses were terminal. The authors of an article in *The Lancet* about the seven cases made the following observation,

Pain was not a prominent clinical issue in our study. Fatigue, frailty, depression and other symptoms contributed more to the suffering of patients.⁶

Clearly, then, it is a fact that there are many cases of euthanasia and assisted suicide, across distinct legislative contexts, that have occurred on grounds other than physical pain, let alone unbearable physical pain.

Euthanasia for Non-Physical Pain

There is no doubt that mental, like physical, pain can be intense, and the parity argument has been used to suggest that it is discriminatory to deny assisted death to those suffering in this way.⁷ However, there are at least two problems with opening assisted dying to psychiatric patients.

⁴ Health Canada (2021) Second annual report on medical assistance in dying in Canada 2020. See <https://www.canada.ca/content/dam/hc-sc/documents/services/medical-assistance-dying/annual-report-2020/annual-report-2020-eng.pdf> Accessed 10 Nov 2021.

⁵ Oregon Health Authority, Public Health Division, Center for Health Statistics (2021) Death with Dignity Act, 2020 Data Summary, p12.

See <https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year23.pdf>

Accessed 19 Jan 2023.

⁶ Kissane D *et al.*, Seven deaths in Darwin: case studies under the Rights of the Terminally Ill Act, Northern Territory, Australia. *The Lancet* 352:1097-1102, 1998.

⁷ Nicolini ME *et al.* (2019) Parity Arguments for ‘Physician Aid-in-Dying’ (PAD) for Psychiatric Disorders: Their Structure and Limits. *Am J Bioethics* 19(10):3-7.

First, mental illness is often poorly understood, and treatments vary in efficacy and availability. If GPs are unaware of newer treatments or fail to seek psychiatric support, as currently happens⁸, patients will miss out on potentially beneficial treatments and instead be euthanised or assisted in suicide. Second, mental illness can be caused by social factors that may seem intractable. Assisted dying could then become a cost-efficient substitute for the task of changing the social and economic conditions which are known to trigger mental illness.

Cases of psychiatric euthanasia have steadily risen in both Holland and Belgium. In Holland the numbers have increased from 0 in 2008 to 83 in 2017.⁹ Cases include euthanasia for depressive disorders, personality disorders, psychosis, post-traumatic stress or anxiety, eating disorders, substance abuse, prolonged grief, and autism.¹⁰ Notably, 70% involve women. The increasing incidence is similar in Belgium. The following are examples of psychiatric euthanasia cases from the notes of attending physicians:

The patient indicated that she had had a life without love and therefore had no right to exist (case 2012-46).¹¹

The patient was an utterly lonely man whose life had been a failure (case 2013-21).¹²

She suffered from the meaninglessness of her existence, the lack of a prospect of a future and the continuous feeling of finding herself in a black hole ... she experienced deep despair and loneliness [Patient 2015-32].¹³

In reality, it is difficult to predict the prospects of recovery for people with depression.¹⁴ Belgian psychiatrist Joris Vandenberghe argues, "I'm convinced that in Belgium, people have died where there were still treatment options and where there was still a chance for years and even decades of life."¹⁵

Euthanasia/Assisted Suicide for Burdensomeness; Lack of Support for Disability

Even putting aside legal expansion of cases, there is a troubling incidence of requests for euthanasia or assisted suicide because people perceive themselves to be a burden to others. Studies have consistently shown that there are people who request euthanasia for this reason and some key figures have even argued that individuals should be entitled to euthanasia if they feel themselves to be a burden.¹⁶ Nor is it easy to screen out such cases, as Lord Sumption pointed out in a landmark ruling of the UK Supreme Court in 2014.¹⁷

⁸ Roy K (2016) Role of psychiatrists in assisted dying: a changing trend. *Am J Psychiatry Res J* 11(9):5-7.

⁹ Evenblij K *et al.* (2019) Euthanasia and physician-assisted suicide in patients suffering from psychiatric disorders: a cross-sectional study exploring the experiences of Dutch psychiatrists. *BMC Psychiatry* 19:74.

¹⁰ Kim SYH *et al.* (2016) Euthanasia and Assisted Suicide of Patients With Psychiatric Disorders in the Netherlands 2011 to 2014. *JAMA Psychiatry* 73(4):362-368

¹¹ Dutch recipient of euthanasia or assisted suicide. Cited by Kim SYH *et al.* (2016) *Op. Cit.*

¹² *Ibid*

¹³ Dutch recipient of euthanasia or assisted suicide. Cited by Kim SYH *et al.* (2018) Suicide and Physician-Assisted Death for Persons With Psychiatric Disorders: How Much Overlap? *JAMA Psychiatry* 75(11):1099-1100.

¹⁴ Nicolini ME *et al.* (2022) Irremediability in psychiatric euthanasia: examining the objective standard. *Psychological Medicine* (online): 1-19.

¹⁵ Lane C (2018) How many botched cases would it take to end euthanasia of the vulnerable. *The Washington Post* https://www.washingtonpost.com/opinions/how-many-botched-cases-would-it-take-to-end-euthanasia-of-the-vulnerable/2018/01/24/bf311400-0124-11e8-8acf-ad2991367d9d_story.html Accessed 20 Dec 2022.

¹⁶ "... if somebody absolutely, desperately wants to die because they're a burden to their family, or the state, then I think they too should be allowed to die. Actually, I've just written an article called 'A Duty to Die?' for a Norwegian periodical. I wrote it really suggesting that there's nothing wrong with feeling you ought to do so for the sake of others as well as yourself." Warnock Baroness BM (2008) Dementia sufferers may have a "duty to die." *Telegraph*. See <http://www.telegraph.co.uk/news/uknews/2983652/Baroness-Warnock-Dementia-sufferers-may-have-a-duty-to->

In fact, those who are ill don't need any encouragement to feel that the financial and personal costs associated with their care make them a burden to their loved ones. Nearly half of Americans would consider an alternative such as assisted death because they do not want to burden their families.¹⁸ In their systematic review of self-perceived burden, McPherson *et al.* found that between 19% and 65% of terminally ill patients reported it as a significant issue.¹⁹ Some studies identified in their review went further and specifically linked the perception of being a burden to a desire for hastened death.²⁰²¹

As Jecker points out, intentionally or unintentionally providing a legalised route to assisted dying for those living with the widespread perception of themselves as a burden endangers their lives and is unbecoming to a society that upholds the values of equality and protection of the vulnerable.

... in a just society, the elderly would worry much less about being a burden. They would feel confident that society would afford them a basic level of care. When the elderly express concerns about being a burden, the proper response is not to suggest they have a duty to die. Instead, it is to commit to becoming a more just society.²²

Just as perceived burdensomeness contracts choices, or conditions them, the same is true for disability.

Social attitudes to disability mean that options are contracted. When there are "difficulties navigating social and financial services, stress of chronic stigma and discrimination, the loss, or threat of loss of independent living, and institutionalization or hospitalization"²³, some will be pushed to the point of accepting euthanasia or assisted suicide. In the words of one disabled scholar,

...the establishment of assisted suicide as clinical and public policy will reinforce social conditions that contribute to disabled people's despair.²⁴

[die.html](#). Accessed 20 Mar 2020.

¹⁷ Lord Sumption observes in his judgement:

"The great majority of people contemplating suicide for health-related reasons, are likely to be acutely conscious that their disabilities make them dependent on others. These disabilities may arise from illness or injury, or indeed (a much larger category) from the advancing infirmity of old age. People in this position are vulnerable. They are often afraid that their lives have become a burden to those around them. The fear may be the result of overt pressure, but may equally arise from a spontaneous tendency to place a low value on their own lives and assume that others do so too. Their feelings of uselessness are likely to be accentuated in those who were once highly active and engaged with those around them, for whom the contrast between now and then must be particularly painful. These assumptions may be mistaken but are none the less powerful for that. The legalisation of assisted suicide would be followed by its progressive normalisation, at any rate among the very old or very ill. In a world where suicide was regarded as just another optional end-of-life choice, the pressures which I have described are likely to become more powerful. It is one thing to assess some one's mental ability to form a judgment, but another to discover their true reasons for the decision which they have made and to assess the quality of those reasons. I very much doubt whether it is possible in the generality of cases to distinguish between those who have spontaneously formed the desire to kill themselves and those who have done so in response to real or imagined pressure arising from the impact of their disabilities on other people. There is a good deal of evidence that this problem exists, that it is significant, and that it is aggravated by negative modern attitudes to old age and sickness-related disability. Those who are vulnerable in this sense are not always easy to identify (there seems to be a consensus that the factors that make them vulnerable are variable and personal, and not susceptible to simple categorisation)." Trinity Term [2014] UKSC 38 On appeal from: [2013] EWCA Civ 961, para 228.

¹⁸ Blendon RJ *et al.* (1992) Should Physicians Aid Their Patients in Dying? The Public Perspective. *JAMA* 267(19):2658-2662.

¹⁹ McPherson CJ *et al.* (2007) Feeling like a burden to others: a systematic review focusing on the end of life. *Palliative Medicine* 21:115-128.

²⁰ Morita T *et al.* (2004) Desire for Death and Requests to Hasten Death of Japanese Terminally Ill Cancer Patients Receiving Specialized Inpatient Palliative Care. *J Pain Sympt Management* 27(1):44-52.

²¹ Jecker NS (2014) Against a Duty to Die. *Am Med Soc J Ethics* 16(5):390-394.

²² *Ibid*

²³ National Council on Disability (2019) *The Danger of Assisted Suicide Laws, Bioethics and Disability Series*, P12. See https://ncd.gov/sites/default/files/NCD_Assisted_Suicide_Report_508.pdf Accessed 24 November 2019.

²⁴ Gill CJ (2010) No, we don't think our doctors are out to get us: Responding to the straw man distortions of disability rights arguments against assisted suicide. *Disability & Health J* 3:31-38.

In a recent case from Canada, a man with a disability sought medical assistance in dying (MAiD) because of fear of homelessness. One doctor has signed off on that request. Commenting on the case, bioethicist Kerry Bowman from the University of Toronto made the following observations:

Cases like [Farsoud's] are emerging with increasing frequency across the country. We were unbelievably naive as a nation to think that vulnerability, disability, poverty that we could parcel that off and it wasn't going to be a problem. It's a huge problem. I worry about this because it is people living with disability, people living with pain, people living in poverty, that are requesting medical assistance in dying, not because of the physical experience they're going through, but because of the social circumstances themselves and this is wrong. It's really a very terrible thing.²⁵

Euthanasia Without Informed Consent

Voluntarism is argued to be an essential element of an assisted dying law. And yet where evidence exists, most notably from Holland and Belgium, even where the law demands a voluntary choice, non-voluntary euthanasia occurs. This may be because it is considered inequitable to deny the 'benefit' of death to those unable to ask for it.

Non-voluntary, active euthanasia by practitioners, which goes beyond the lawful performance of voluntary euthanasia, is not even described as euthanasia. As de Diesbach observes,

In some cases where the patient is deemed not to be able to discern matters for him/herself as required for an informed request for euthanasia, because of his/her young age or mental deficiency, the medical teams appear to invoke "a case of necessity". This refers to the possibility of ending a person's life in the event of unbearable or unremitting suffering, without the patient having made such a request. Dr M. Englert, an instructor with the EOL [End of Life] Forum writes: "In the case of a new-born infant or very young patients who are unable to make such a request, the active ending of life is not considered to be euthanasia but rather an act which arises out of the observation that one is faced with a case of necessity, as is the case of active ending of the life of an adult patient who is not conscious and has not made a prior request for euthanasia".²⁶

de Diesbach continues,

What is the difference between the active ending of a person's life and euthanasia?... Authorizing the medical team to invoke a case of necessity, thereby justifying euthanasia, beyond all the conditions provided for by the law, gives the medical team arbitrary and uncontrollable power.²⁷

Cases of non-voluntary euthanasia of adults in Holland and Belgium are known to occur in large numbers. Dutch reports for 1990 and 1995 showed that approximately 1000 deaths per year involved 'ending of life without patient's explicit request'.²⁸ However, the same reports show that many more patients were overdosed with opioids explicitly to end life, approximately 40% of whom made no request.²⁹ There has been a large and steady increase in deaths within this category from

²⁵ Mulligan C & Bond M (2022) Ontario man applying for medically-assisted death as alternative to being homeless. *CityNews* See <https://toronto.citynews.ca/2022/10/13/medical-assistance-death-maid-canada/> Accessed 27 Dec 2022.

²⁶ de Diesbach E *et al.* (2012) Euthanasia in Belgium: 10 years on. Dossier of the *European Institute of Bioethics* See <https://www.ieb-eib.org/en/file/end-of-life/euthanasia-and-assisted-suicide/euthanasia-in-belgium-10-years-on-319.html?backto=search> Accessed 25 Feb 2020.

²⁷ *Ibid*

²⁸ van der Maas PJ *et al.* (1996) Euthanasia, physician-assisted suicide, and other medical practices involving the end of life in The Netherlands, 1990-1995. *New Engl J Med* 335(22):1699-1705.

²⁹ Hendin H (2002) The Dutch Experience. In: *The Case against Assisted Suicide. For the Right to End-of-Life Care*. Eds Foley

2001 to 2015 (20% to 36% respectively),³⁰ more than enough to account for a small decline in deaths within the category 'ending of life without patient's explicit request' (0.7% in 2001 to 0.3% in 2015). Overall, it is clear that cases involving intentionally ending life without request have increased with time. In Belgium, the reported rates of non-voluntary euthanasia are even higher than in Holland, but in more recent years poor reporting makes a definitive assessment of numbers impossible. Nevertheless, other studies provide some insight into non-voluntary euthanasia in Belgium. The first, by Chambaere *et al.*, involved a survey of Belgian physicians.³¹ The second, by Inghelbrecht *et al.*, also published in 2010, surveyed nurses who were involved in the care of patients who "received a potential life-ending decision".³²

In the Chambaere study, 208 cases involving life-ending drugs were reported. Of these, 142 were with an explicit request (68%) and 66 were without one (32%). In 51 of the 66 cases, the decision was not discussed with the patient. Given that the response rate for this survey was only 58.4%, it seems likely some physicians may not have responded if worried that they had participated in illegal activities. It is known that euthanasia is under-reported in Belgium. One study found that only approximately half of all cases of euthanasia were reported.³³ A Belgian news report has claimed that only 1 in 4 doctors make official reports.³⁴

In the study by Inghelbrecht *et al.*, nearly half of nurses had participated in life terminations without an explicit request. Whereas 12% of nurses administered life-ending drugs in cases with an explicit request, 45% did so when there was no explicit request, taking over from doctors in such cases.

Euthanasia for Dementia

Baroness Warnock once observed:

If you're demented, you're wasting people's lives - your family's lives - and you're wasting the resources of the National Health Services.³⁵

Euthanasia of dementia patients is rarely if ever discussed when the initial demand for assisted dying laws is made, presumably because it would violate voluntarism. Yet the resulting pressure to euthanise such persons is strong for various reasons such as the burden of care in the face of a lack of resources, or projection of the carer's own horror of living in a demented state.

K & Hendin H, John Hopkins University Press, Baltimore, 105.

³⁰ van der Heide A *et al.* (2017) End-of-Life Decisions in the Netherlands over 25 Years. *New Engl J Med* 377(5):492-494.

³¹ Chambaere K *et al.*, Physician-assisted deaths under the euthanasia law in Belgium: a population-based survey. *Canadian Medical Association Journal*, 182(9):895-901, June 15, 2010.

³² Inghelbrecht E *et al.*, The role of nurses in physician-assisted deaths in Belgium. *Canadian Medical Association Journal* 182(9):905-910, June 15, 2010.

³³ Smets T, *et al.*, Reporting of euthanasia in medical practice in Flanders, Belgium: cross sectional analysis of reported and unreported cases. *British Medical Journal*, 341:5174, 2010. The following quote is from the study: "The reporting rate for euthanasia in Flanders in 2007 is estimated to be 52.8%. This means that only one out of two cases of actual euthanasia is reported to and reviewed by the Federal Control and Evaluation Committee, and one in two is not. The most important reason given by physicians for not reporting a case to the review committee was that the physician did not perceive the act to be euthanasia (76.7%). A large majority of the unreported cases (92.2%) were in fact acts of euthanasia as defined in our study but were not perceived or labeled as "euthanasia" by the physician involved. Unreported cases of euthanasia were generally dealt with less carefully than reported cases: a written request for euthanasia was absent more often; other physicians and care givers specialised in palliative care were consulted less often; the life ending act was more often performed with opioids, sedatives, or both; and the life ending drugs were more often administered by a nurse instead of a physician."

³⁴ More Cases of Euthanasia in Belgium, see <http://www.deredactie.be/cm/vrtnieuws.english/news/1.745723> Accessed 18 January 2023.

³⁵ Warnock Baroness BM (2008) Dementia sufferers may have a "duty to die." *Telegraph*. <http://www.telegraph.co.uk/news/uknews/2983652/Baroness-Warnock-Dementia-sufferers-may-have-a-duty-to-die.html>. Accessed 20 Mar 2020.

Euthanasia of dementia patients, whose voluntary choices are limited or absent, has been increasing in Holland – from 12 in 2009 to 169 in 2017.^{36 37} Controversy exists about how many of these patients were deemed competent at the time of euthanasia. In Belgium, while officially there were only 14 cases of euthanasia of dementia patients (2013),³⁸ all of whom were deemed competent, separate research from 2010 showed that somewhere in the vicinity of 200 dementia patients were euthanised without either contemporaneous consent or an advance directive within the category ‘ending of life without patient’s explicit request’.^{39 40} While no equivalent research exists for Holland it is likely that something similar pertains.

In a case that has attracted global attention, a Dutch court recently acquitted a doctor of any wrongdoing after she gave a lethal injection to a woman with dementia.⁴¹ The woman had previously expressed a wish to be euthanised at the time of her choice, but when the doctor and family decided the time had come, she resisted. The doctor and family nevertheless deemed her unable to state her wishes.⁴² As she resisted the lethal injection, family members restrained her to enable completion of the act.⁴³

Euthanasia for Minors and Infants

Similarly, no one argues for euthanasia of minors or infants at the outset. And yet both now occur in Holland and Belgium. In The Netherlands from 2005 to 2018, official reports indicate that only 14 children between the ages of 12 and 18 were actively euthanised; that is, about 1 per year.⁴⁴ If the timeframe is restricted to the 10 years leading up to 2014, only 5 cases of euthanasia of minors were reported (one every 2 years).⁴⁵ Unfortunately, there appears to be no published research (as opposed to official reports) that can reveal more accurately the prevalence of active euthanasia of minors for this time period. There was a death certificate study of children aged 1 to 17 in 2001 (before the law permitted euthanasia of minors), in which it was found that there were about 5 cases per year (0.7% of all deaths of minors, narrowly defined as only those with a request from the child).⁴⁶ Importantly, another 15 children per year (2.0%) were actively euthanised with no specific request from the child, but instead one from the parents. These figures from 2001 are unlikely to have changed dramatically in the years leading up to 2014, so it is almost certain that the reporting rate is low and figures around 15 – 20 cases of lethal injection occur per year for 1 – 17-year-olds.

³⁶ de Beaufort ID & van de Vathorst S (2016) Dementia and assisted suicide and euthanasia. *J Neurol* 263:1463–1467.

³⁷ Cited by Bravo G *et al.* (2019) Comparing the attitudes of four groups of stakeholders from Quebec, Canada, toward extending medical aid in dying to incompetent patients with dementia. *Int J Geriatr Psychiatry* 34:1078–1086.

³⁸ Dierickx S *et al.* (2017) Euthanasia for people with psychiatric disorders or dementia in Belgium: analysis of officially reported cases. *BMC Psychiatry* 17:203.

³⁹ Bilsen J *et al.* (2009) Medical End-of-Life Practices under the Euthanasia Law in Belgium. *N Engl J Med* 361(11):1119–1121.

⁴⁰ Chambaere K *et al.* (2010) Physician-assisted deaths under the euthanasia law in Belgium: a population-based survey. *Can Med Assoc J* 182(9):895–901.

⁴¹ In April 2020, the Dutch Supreme Court ruled the case permissible. See <https://www.bbc.com/news/world-europe-52367644>. Accessed 23 April 2020.

⁴² Holligan A (Sept 2019) Dutch euthanasia case: Doctor acted in interest of patient, court rules. See <https://www.bbc.com/news/world-europe-49660525> Accessed 11 Feb 2020.

⁴³ Under investigation, the geriatrician involved “reported to the euthanasia review committee that ‘the patient was not mentally competent, so her utterance at (the moment of euthanasia) was not relevant in the physician’s opinion. Even if the patient had said at that moment: “I don’t want to die”, the physician would have continued with the termination of life.” See Miller DG *et al.* (2019) Advance euthanasia directives: a controversial case and its ethical implications. *J Med Ethics* 45:84–89.

⁴⁴ Egan R (2018) Child euthanasia in the Netherlands and Belgium. *Euthanasia Prevention Coalition Blog* See <http://alexschadenberg.blogspot.com/2018/08/child-euthanasia-in-netherlands-and.html> Accessed 5 Feb 2020.

⁴⁵ Rietjens JAC *et al.* (2014) Letters (To the Editor) Euthanasia for Minors in Belgium. *JAMA* 312(12):1258–1259.

⁴⁶ Vrakking AM *et al.* (2005) Medical End-of-Life Decisions for Children in the Netherlands. *Arch Pediatr Adolesc Med* 159:802–809.

In Belgium in 2007/2008, a death certificate study revealed that while there were no cases of active euthanasia narrowly defined as by request only, 7.9% of all deaths were in fact active euthanasia (by lethal drugs) without an explicit request from the child, amounting to about 10 per year in Flanders alone.⁴⁷ This figure is nearly 4 times the rate in The Netherlands (7.9% v. 2.0%), albeit over different periods. This occurred at a time when euthanasia of minors was illegal in Belgium. It is likely that the numbers increased after the law changed in 2014.

In addition to minors, euthanasia of infants has been happening in Holland and Belgium for many years. In Dutch and Belgian reports up till 2010, between 7% and 9% of all infant deaths involved active euthanasia, that is, a lethal injection.^{48 49} More recent reports almost certainly underestimate the rate because practitioners fail to report cases, some of which they consider *not* to be euthanasia even though a lethal injection was used.⁵⁰

Conclusion

Laws that enable members of the medical profession to terminate the lives of their patients come at a cost. However restrictive they might seem initially; their effects cannot be contained: the different values that undergird euthanasia and assisted suicide for hard cases contain within them the seeds of expansion well beyond those cases. While some of the changes have developed more slowly in countries like Holland and Belgium, the slide has been far more rapid in countries like Canada. It is too soon to see whether others like Australia will follow, but there is reason for pessimism.

It might be argued that assisted dying regimes are grounded in voluntarism and only those who voluntarily choose death will access the system but, in reality, it is the vulnerable whose choices are constrained and who 'choose' death because the community has failed them. For them, euthanasia and assisted suicide are an 'indecent proposal' that they perceive as a statement about the value of their lives when compared with those of others. Worse still, some who are simply unable to choose at all are euthanised because others perceive their death to be a benefit. The question is, a benefit to whom?

Even from the selection of evidence we have surveyed in this brief submission we can get a sense of the bleak reality that can follow when euthanasia and assisted suicide become public policy. The resulting detriment to society is demonstrable: not only does assisted dying devalue the lives of some members of society, but it can introduce the threat of death to some of the most vulnerable members including those who feel like a burden; disabled people whose needs are unmet; children and babies; those with dementia or mental health issues; those experiencing deep loneliness and fear.

⁴⁷ Pousset G *et al.* (2010) Medical End-of-Life Decisions in Children in Flanders, Belgium. A Population-Based Postmortem Survey. *Arch Pediatr Adolesc Med* 164(6):547-553.

⁴⁸ Cate K *et al.* (2015) End-of-life decisions for children under 1 year of age in the Netherlands: decreased frequency of administration of drugs to deliberately hasten death. *J Med Ethics* 41(10):795-798.

⁴⁹ Provoost V *et al.* (2005) Medical end-of-life decisions in neonates and infants in Flanders. *Lancet* 365:1315-1320.

⁵⁰ Ten Cate K *et al.* (2015) *Op. Cit.*