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# Euthanasia and Assisted Suicide

*When Choice is an Illusion and Informed Consent Fails*



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## Euthanasia and Assisted Suicide – When Choice is an Illusion and Informed Consent Fails

Gregory K Pike, 2020

### Executive Summary

- Arguments for legalising euthanasia and assisted suicide always rely upon the assertion that a patient must always make a persistent, well-considered, and free choice to end his or her life. In other words, that currently accepted standards of fully informed consent in medical practice must apply.
- However, in those jurisdictions where euthanasia and/or assisted suicide are legal, the evidence shows that a large minority, or in some categories a majority of cases, occur where choice is absent, seriously compromised, or subject to unacceptable coercion and pressure.
- An obvious example concerns infant euthanasia. In Dutch and Belgian reports up till 2010, between 7% and 9% of all infant deaths involved active euthanasia, that is, a lethal injection. More recent reports almost certainly underestimate the rate because practitioners fail to report cases, some of which they considered *not* to be euthanasia even though a lethal injection was used.
- Cases of non-voluntary euthanasia of adults in Holland and Belgium 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’. However, the same reports show that many more patients were overdosed with opioids explicitly to end life, approximately 40% of whom made no request. There has been a steady and large increase in deaths within this category from 2001 to 2015 (20% to 36% respectively), more than enough to account for a decline in deaths within the category ‘ending of life without patient’s explicit request’ (0.7% in 2001 to 0.3% in 2015). Overall, cases involving intentionally ending life without request have likely 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.
- Euthanasia can occur via omission when there is an intention to end life. Deeply sedating while removing food and fluids (continuous deep sedation; CDS) can end life when that is the intended goal. Early Dutch reports did not expressly record cases of CDS; however, in 1990 there were 8750 cases of treatment withholding or withdrawal with an intention to hasten death and without request; that is; non-voluntary euthanasia by omission. From 2005 onwards, cases of CDS were recorded and increased from 8.2% of all deaths in 2005 to 18.3% in 2015.
- In Switzerland the incidence of CDS nearly quadrupled from 6.7% in 2001 to 24.5% in 2013. The proportion in which there was an intention to hasten death more than doubled over that timeframe, but patient consent was not recorded.
- Euthanasia by omission also occurs when food and fluids are withdrawn from patients with a prolonged disorder of consciousness when the intention is to end life. There are estimated to be 24,000 such patients in the UK who may be at risk of euthanasia by omission.
- Euthanasia where choice is *compromised* via a deficiency in capacity include cases of patients who are minors, suffer from dementia, or have psychiatric disorders.
- There is limited information from either Holland or Belgium about euthanasia of minors, either by active means or by omission. Some Dutch reports suggest 1 minor per year receives

euthanasia; other research suggests the figure is more likely around 5 cases per year, with a further 15 without request from the minor. In Flanders alone for 2007/2008, 7.9% (10 per year) of all euthanasia deaths of minors occurred without explicit request. Euthanasia of minors by omission, whether by CDS or other means, is so poorly reported that not even an estimate can be made.

- Euthanasia of dementia patients has been increasing in Holland – from 12 in 2009 to 169 in 2017. 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), all of whom were deemed competent, separate research from 2010 showed that somewhere in the vicinity of 200 dementia patients were euthanased without consent or an advance directive within the category ‘ending of life without patient’s explicit request’. While no equivalent research exists for Holland it is likely that something similar pertains. There is almost no research on euthanasia of dementia patients by omission. One Belgian study found 9% of patients with dementia received CDS, nearly all of whose dementia was advanced.
- The euthanasia of psychiatric patients is deeply controversial. In Holland the numbers have increased from 0 in 2008 to 83 in 2017. Cases include for depressive disorders, personality disorders, psychosis, posttraumatic stress or anxiety, eating disorders, substance abuse, prolonged grief, and autism. 70% are women. The numbers and increasing incidence is similar in Belgium.
- Euthanasia in the context of pressure, coercion, undue influence and cultural expectation is difficult to identify, but involves patients with particular vulnerabilities. These include where euthanasia is used for organ donation, for prisoners, for those who perceive themselves as burdensome to others, and for persons with a disability. Pressure can be subtler in the context of suicide contagion and when euthanasia and/or assisted suicide become entrenched as culturally accepted practices.
- Since 2005, in Holland and Belgium at least 70 people have donated organs via euthanasia. In Canada the rate has been much higher, where 30 people donated organs via euthanasia over a three-year period from 2016 to 2018. This number increased for the first 11 months of 2019, where there were 18 donors in Ontario alone.
- Euthanasia for prisoners is rare but under serious consideration in Belgium and Canada. At least one prisoner has been euthanased in Canada, and many more have made requests.
- Perceiving oneself as a burden near the end of life is common and sometimes encouraged by authority figures and others. Self-perceived burdensomeness has been consistently cited as a reason for seeking euthanasia and assisted suicide. Increasing levels of elder abuse put vulnerable people at greater risk when euthanasia is accepted. Moreover, the financial burden associated with end of life care is the elephant in the room for the euthanasia debate.
- People with a disability are at particular risk in cultures that accept euthanasia and/or assisted suicide. Assisted suicide proponents have been characterized as “white, well-off, worried, and well”, who fail to understand the disproportionate impact of an option of assisted suicide upon people who are socially marginalized and whose limited options for genuine care and support seriously limit their autonomous choices.
- Suicide contagion is an established phenomenon that operates for assisted suicide as well as unassisted suicide. Media reporting of assisted suicide cases has been linked to a contagion effect for both. Assisted suicide rates in Switzerland doubled for men and tripled for women from 1991 to 2008. Assisted suicides in Oregon have increased year on year from 16 in 1998 to 188 in 2019.
- Establishing a cultural expectation to accept euthanasia is exemplified in a potential new category for euthanasia in Holland, namely for those tired of life, where otherwise healthy

individuals over the age of 70 would ‘choose’ euthanasia. The proposal has significant support in that country. Such a change, if adopted, will establish a norm that operates as a cultural pressure upon elderly isolated, lonely, and unwanted souls who perceive that the rest of the community has no interest in their continued existence. They may feel they should just take the pill or accept the injection. Such a choice might in reality be no choice at all.

## Introduction

Advocacy for euthanasia typically centres on patient autonomy. This is conveyed by use of the term ‘voluntary euthanasia’, which requires that a choice must be freely and persistently made. For something as grave and final as inducing death, ensuring that such a choice is truly free demands special attention, so the argument goes, and hence distinctive safeguards are needed. There is no going back. Unlike with other medical treatments, and euthanasia is framed in the context of medical treatment, there can be no ongoing refinement, no recourse to alternatives if a treatment is not working, and no hope that a new avenue for healing may emerge. Euthanasia is in a category of its own.

This paper will examine what the evidence tells us about the reality of choosing euthanasia in jurisdictions where it is legal. This will necessitate consideration of the nature and extent of euthanasia for those who do not have the capacity to decide or have significantly compromised capacity. These are cases of non-voluntary euthanasia<sup>1</sup>. This paper will also consider what a free choice means even for those who have capacity, and how free such a choice can really be from coercion, pressure and undue influence. Furthermore, in cultures where euthanasia has had time to develop, when it has become a customary part of life and death, how genuinely free is a choice of such gravity in practice?

In this paper, euthanasia will be defined as the intentional taking of human life by a deliberate act such as lethal injection, whatever pharmaceutical agent is used, or the denial of reasonable care with the intention to induce death. The former is sometimes called active euthanasia or euthanasia by commission, and the latter passive euthanasia or euthanasia by omission. The terms active euthanasia and euthanasia by omission will be used throughout. Euthanasia by omission is to be distinguished from the withdrawal of medical treatment that is futile<sup>2</sup> or overly burdensome and disproportionate to benefit, and where there is no intention to induce death. Active treatments that might shorten life, but without the intention to induce death, are also not euthanasia. For example, the use of proportionate pain medication where there is a possibility that life may be foreshortened can be justifiable with recourse to the principle of double effect. In contrast, practices like continuous deep sedation (CDS, sometimes also called terminal sedation), where sedation is often coupled with the denial of food and fluids to those who are not imminently dying, with the intention to induce death, constitute euthanasia by omission.

The place of intention is central to the definition of euthanasia. When the goal of the act is to end the person’s life, the operator’s intention is often, but not always, apparent. The ending of life is the

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<sup>1</sup> The term ‘non-voluntary euthanasia’ refers to cases where there has been no explicit or implicit consent to be euthanased. One blog writer has defined such cases as those involving “deliberate and beneficent killing that is neither wholly for nor wholly against the patient’s wishes” (author not identified, *The Complexity of Non-Voluntary Euthanasia*, *J Med Ethics* June 24, 2010. See <https://blogs.bmj.com/medical-ethics/2010/06/24/the-complexity-of-non-voluntary-euthanasia/> Accessed 26 Nov 2019). These include such cases as infants, children and patients with advanced dementia or other degenerative and debilitating conditions, or those who are in minimally conscious states. Cases of non-voluntary euthanasia can be distinguished from cases of *involuntary* euthanasia, where the wishes of the patient are contravened. The same blog writer referred to above has argued that there is actually no such thing as involuntary euthanasia. Such cases are acts of intentional killing of patients with capacity against their wishes, expressed or otherwise. One might argue these are simply acts of homicide, albeit potentially from a motive of compassion.

<sup>2</sup> For a discussion of the complexity of judgements about futility, and how such judgements can become confused with other ethically significant considerations, and in doing so become more correctly understood as examples of euthanasia by omission without consent, see Nair-Collins M (2017) Medical futility and involuntary passive euthanasia. *Perspectives in Biology and Medicine* 60(3):415-422.

measure of success, which may be achieved in a variety of ways – by act or omission, by barbiturates or opiates, by denial of reasonable care, and so forth. The means are directed towards the goal, which is to end life. Various declarations, such as that of the *Parliamentary Assembly of the Council of Europe* in its 2012 declaration, prohibit *intentional* killing by act or omission.<sup>3</sup>

There are some jurisdictions where euthanasia is not permitted, but assisted suicide is, with the terms Physician Assisted Dying or Physician Aid-in-Dying (both often use the acronym PAD) sometimes used collectively regarding both. Assisted suicide is morally similar to euthanasia and will also form part of the evidence base for this paper. Assisted suicide, like euthanasia, demands from the medical profession an active role in ending the life of a patient. While acts of non-voluntary euthanasia do not tend to form part of the evidence base where assisted suicide alone is legal, questions of capacity and compromised choice via coercion, pressure, and undue influence still apply.

### **Informed Consent and Capacity**

In jurisdictions where euthanasia and assisted suicide are legal, medical professionals are the key gatekeepers, the ones who agree or decline to assist with suicide or enact euthanasia. There are powerful arguments against redefining the role of medical practitioners in this way, based upon their central commitment to healing, so it is understandable that more medical practitioners oppose than support euthanasia in, for example, the UK<sup>4</sup>. As Boudreau and Somerville note,

Most physicians accept the healer role as a fundamental and enduring characteristic of the profession.<sup>5</sup>

However, for those who see euthanasia and assisted suicide as medical treatments within their remit, the question arises as to whether the general and accepted standards of medical conduct that govern their professional behavior are being applied. And one of the most important and relevant standards is informed consent.

Informed consent is a process in which a health care provider educates a patient about the risks, benefits, and alternatives of a given procedure or intervention. The patient must be competent to make a voluntary decision about whether to undergo the said procedure. Informed consent is both an ethical and legal obligation of medical practitioners ... The following are the required elements for documentation of the informed consent discussion: (1) the nature of the procedure, (2) the risks and benefits of the procedure, (3) reasonable alternatives, (4) risks and benefits of alternatives, and (5) assessment of the patient's understanding of elements 1 through 4.<sup>6</sup>

In general, the greater the gravity of the intervention, the greater the need for rigour in conducting the consent process. So greater certainty would be required about patient comprehension, availability of alternatives, risks and complications, and pressures on the patient when the consequences are serious, which is unarguably true of inducing death.

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<sup>3</sup> Parliamentary Assembly of the Council of Europe (2012) Resolution 1859, Protecting human rights and dignity by taking into account previously expressed wishes of patients. See article 5, pg 1, “Euthanasia, in the sense of the intentional killing by act or omission of a dependent human being for his or her alleged benefit, must always be prohibited.” See <http://semantic-pace.net/tools/pdf.aspx?doc=aHR0cDovL2Fzc2VtYmx5LmNvZS5pbncvbnQvbnVlcG1sL1hSZWYvWVJILURXLWV4dHluYXNwP2ZpbG VpZD0xODA2NCZsYW5nPUVO&xsl=aHR0cDovL3NlbnVudGljcGFjZS5uZXQvWHNsdc9QZGYvWFJlZi1XRRC1BVVC1YTUwYUERGln hzbA==&xsltparams=ZmlsZWlkPTE4MDYQ> Accessed 17 Jan 2020.

<sup>4</sup> McCormack R *et al.* (2012) Attitudes of UK doctors towards euthanasia and physician-assisted suicide: A systematic literature review. *Palliative Medicine* 26(1):23-33. See more recently <https://www.rcplondon.ac.uk/news/no-majority-view-assisted-dying-moves-rcp-position-neutral> Accessed 02 August 2020.

<sup>5</sup> Boudreau JD & Somerville MA (2013) Euthanasia is not medical treatment. *British Medical Bulletin* 106:45–66.

<sup>6</sup> Gossman W *et al.* (2019) Informed Consent. StatPearls Publishing LLC <https://www.ncbi.nlm.nih.gov/books/NBK430827/>

The process of gaining informed consent is well described in the General Medical Council (GMC) document *Consent: Patients and Doctors Making Decisions Together*<sup>7</sup>, guidance that is virtually the same worldwide. The guidance requires doctors to be appropriately qualified to provide information about all possible treatments, skilled in the diagnosis of mental health problems (particularly as regards capacity), and able to provide information about benefits, risks, complications and side effects of the various treatments available. Doctors must also be aware that with the shift in emphasis away from medical paternalism, risks that the patient deems significant are relevant, and not simply what the doctor might think relevant.<sup>8</sup> Hence, where euthanasia and/or assisted suicide are legal, complications such as vomiting, prolongation of death, and re-awakening, each with a relatively high incidence, must legally be discussed.<sup>9</sup>

Informed consent typically requires medical treatments that are deemed beneficial to a patient to be *offered*, the patient relying on a professional whose expertise and experience they trust. So if euthanasia and assisted suicide are indeed beneficial medical treatments, then according to accepted informed consent standards, a practitioner should raise them in discussion about treatment options. But this is precisely *not* what most think should happen. Instead, it is argued that any discussion about euthanasia should originate from the patient. This is another reason why euthanasia does not sit well within the paradigm of medicine.

When it comes to the question of coercion, pressure or undue influence to accept medical treatment, the GMC advice notes that legal precedent has established that under such circumstances, consent may not be valid.<sup>10</sup> For assisted suicide and euthanasia, to what extent such problems are adequately investigated by practitioners is unclear, although there are troubling signs to be explored later that coercion, pressure, and undue influence are not only likely, but already quite evident.

### *Capacity and Consent*

In addition to the usual informed consent discussions, there will be circumstances when decisions about medical treatments must be made when the patient is not in a position to decide; that is, when they lack capacity.

Capacity refers to an assessment of the individual's psychological abilities to form rational decisions, specifically the individual's ability to understand, appreciate, and manipulate information and form rational decisions.<sup>11</sup>

Questions of capacity hold particular relevance for euthanasia given the many assurances that it would only be available to those *with* capacity. If the evidence were to show otherwise, then that would be of paramount significance not only for current practice, but also for future decision-making.

In reality, determinations of capacity are not always straightforward. As the GMC advice notes,

A patient's ability to make decisions may depend on the nature and severity of their condition, or the difficulty or complexity of the decision. Some patients will always be able to make simple decisions, but may have difficulty if the decision is complex or involves a number of options. Other patients may be able to make decisions at certain

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<sup>7</sup> General Medical Council (2008) *Consent: Patients and Doctors Making Decisions Together*, See [https://www.gmc-uk.org/-/media/documents/Consent\\_English\\_0617.pdf](https://www.gmc-uk.org/-/media/documents/Consent_English_0617.pdf) 48903482.pdf

<sup>8</sup> The standard for informed consent in the UK was redefined by *Montgomery v Lanarkshire*. Deciding about risk disclosure shifted from the "reasonable doctor" to the "reasonable patient". (See <https://www.medicalprotection.org/uk/articles/new-judgment-on-patient-consent> Accessed 28 Nov 2019).

<sup>9</sup> Sinmyee S *et al.* (2019) Legal and ethical implications of defining an optimum means of achieving unconsciousness in assisted dying. *Anaesthesia* 74:630–637.

<sup>10</sup> For example, with reference to *Re T (Adult) [1992] 4 All ER 649*, doctors are advised that "A patient's consent to a particular treatment may not be valid if it is given under pressure or duress exerted by another person..." GMC (2008) *Op. Cit.* p39.

<sup>11</sup> Leo RJ (1999) Competency and Capacity to Make Treatment Decisions: A Primer for Primary Care Physicians. *Primary Care Companion J Clin Psychiatry* 1:131-141.

times but not others, because fluctuations in their condition impair their ability to understand, retain or weigh up information, or communicate their wishes.<sup>12</sup>

The relationship between mental health and capacity is one example of a grey area within which capacity may be compromised rather than absent, and requires from medical practitioners particular care to ascertain to what extent different psychiatric disorders may influence capacity.<sup>13</sup> In the context of euthanasia and assisted suicide, debate about whether either or both should be accessible to psychiatric patients is building, even as such access is already happening. This will be explored later. Nevertheless, the majority of forensic psychiatrists believe the presence of major depressive disorder, for example, should immediately elicit a finding of incompetence to consent to assisted suicide.<sup>14</sup>

In the Australian context, Purser and Rosenfield have argued for the need for collaborative assessment of capacity by doctors and lawyers. They are concerned that there is no nationally consistent approach, leaving too much latitude for miscommunication and misinformation.<sup>15</sup> They argue that medical professionals are not trained to adequately assess legal capacity for advance directives, as well as other legal instruments. If so, then the same could be said to apply to other medical decision-making. Perhaps this is why primary care physicians have been increasingly seeking help with psychiatric assessments of their patients for the determination of capacity.<sup>16</sup> As will be shown, such referral does not appear to apply where euthanasia and assisted suicide occur, at least not to the extent that it should.

Another complication comes with the observation that the personal values of physicians play a significant role in determinations of capacity. Some physicians apply more stringent criteria for more risky procedures, whereas others tend to apply the same criteria regardless of the consequences of the procedure.<sup>17</sup> In the context of euthanasia and assisted suicide, one would of course expect that a physician's moral perspective would influence the decision to *participate* or not, but determinations of capacity for an intervention of such gravity should rest upon objective criteria and adhere to the highest standards of rigour.<sup>18,19</sup> The finding that some physicians' personal values mean that the determination of capacity is the same whether the medical procedure is minor or major is therefore of serious concern. Shaw *et al.* argue that it is only physicians with moral qualms about assisted suicide who may be contaminating their assessment of capacity, unjustifiably raising the bar.<sup>20</sup> However, the opposite may be just as likely, if not more so; namely, that physicians who are morally comfortable with assisted suicide are contaminating *their* assessment of capacity, lowering the bar unjustifiably and in doing so risking the lives of some patients who may actually lack sufficient capacity for a decision like ending their life. When life is at stake, erring on one side seems more troublesome than erring on the other.

The extent to which concepts of mental capacity vary among experts was recently revealed in an analysis by Price *et al.* of oral and written evidence provided to the UK's *Commission on Assisted Dying*.<sup>21</sup> The researchers found that ideas about mental capacity were inconsistent and sometimes at variance with the *Mental Capacity Act 2005*. These differences point to a real problem with the place

<sup>12</sup> GMC (2008) *Op. Cit.* p28.

<sup>13</sup> Klein CC *et al.* (2019) Capacity to provide informed consent among adults with bipolar disorder. *Journal of Affective Disorders* 242:1-4.

<sup>14</sup> Ganzini L *et al.* (2000) Evaluation of Competence to Consent to Assisted Suicide: Views of Forensic Psychiatrists. *Am J Psychiatry* 157:595–600.

<sup>15</sup> Purser KJ & Rosenfield T (2014) Evaluation of legal capacity by doctors and lawyers: the need for collaborative assessment. *Med J Australia* 201(8):483-485.

<sup>16</sup> Leo RJ (1999) *Op. Cit.*

<sup>17</sup> Hermann H *et al.* (2015) Physicians' personal values in determining medical decision-making capacity: a survey study. *J Med Ethics* 41:739-744.

<sup>18</sup> Price A *et al.* (2014) Concepts of mental capacity for patients requesting assisted suicide: a qualitative analysis of expert evidence presented to the Commission on Assisted Dying. *BMC Medical Ethics* 15:32.

<sup>19</sup> Ganzini L *et al.* (2000) *Op. Cit.*

<sup>20</sup> Shaw D *et al.* (2018) Assessment of decision-making capacity in patients requesting assisted suicide. *Brit J Psychiatry* 213:393-395.

<sup>21</sup> Price A *et al.* (2014) *Op. Cit.*

of capacity in decisions about euthanasia or assisted suicide – if even the experts cannot agree, then where does that leave the average primary care physician who must decide whether the person before them has capacity to end their life?

There are two other matters regarding capacity that warrant consideration.

First, when capacity is deemed to be absent, a surrogate decision maker often decides whether a medical treatment can be accepted or not, or withdrawn or not. This is usually someone close to the patient who understands them and their values. What does this mean for euthanasia? While there is typically no formal role given to surrogates to authorize active euthanasia, for cases of non-voluntary euthanasia, clearly someone else is deciding. And when it comes to euthanasia by omission, where treatment is withdrawn with the intention to induce death, surrogates can be legally permitted to act on behalf of a patient. The role of surrogates can be tricky for a range of reasons, whether at the end of life or not; but for euthanasia or assisted suicide, an added complication is that a surrogate may be more directly affected by the outcome. Surrogates agree with assisted dying for patients with advanced dementia at more than twice the rate of physicians.<sup>22</sup>

Second, what is the place of advance directives with respect to euthanasia? When capacity is lost, what does it mean to rely on a previously expressed wish for euthanasia, especially if at the time of euthanasia the patient does not want it? Such directives requesting euthanasia in the Netherlands have been legal for many years, but in the expert evidence presented to the UK's *Commission on Assisted Dying* referred to above, there was unanimous opposition to them. It can be argued that euthanasia of patients on the basis of an advance directive in fact constitutes euthanasia without consent, because a patient without capacity is ultimately being euthanased, and attributing former views on the value of life to a now incompetent person is less defensible than giving effect to previous views on what were felt to be (and may in fact be) burdensome procedures for the individual. The whole point about an advance directive is that it applies when someone lacks capacity.

### **Euthanasia Without Consent**

From the earliest stages of legal euthanasia in Holland, there were concerns that voluntary euthanasia would lead to non-voluntary euthanasia, that legislative permission for euthanasia on request would inevitably lead to euthanasia without request. In other words, that informed consent to euthanasia would initiate a slide towards euthanasia without consent. This slippery slope may be argued on theoretical grounds by using logical argument, and has been termed the logical slippery slope. In addition, the slippery slope may be empirical and hence potentially measurable on evidentiary grounds. Regardless of whether an empirical slippery slope can be proven, evidence about the current extent of non-voluntary euthanasia is important information in and of itself, primarily because support for it is so limited, at least in the case of active euthanasia.

But before discussing the slippery slope from voluntary to non-voluntary euthanasia, it is important to note that there are other forms of slippery slope that are not so specifically defined. Another that is arguably more evident is a slide from voluntary euthanasia for specific hard cases defined in a particular way, to a broader range of cases. Such a slide might be called category expansion, and may occur through changes in guidance documents or amendments to statute law, or case law, or precedent set when legal breaches are not prosecuted. Categories may expand from unbearable physical suffering to unbearable psychological suffering to existential suffering, to suffering however interpreted. Other examples include category expansion from suffering as a required condition to being tired of life; from terminality as a condition to no terminality requirement; from adults to minors to infants; from close medical scrutiny to minimal medical scrutiny – for example, by weakening the conditions from two doctors to one, or permitting nurses or other health professionals to participate, or moving from exclusion of organ donation in the context of euthanasia to permitting it.

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<sup>22</sup> Loizeau AJ *et al.* (2019) Physician and Surrogate Agreement with Assisted Dying and Continuous Deep Sedation in Advanced Dementia in Switzerland. *Neurodegenerative Diseases* 19(1):1-8.



Each of these more nuanced category expansions has occurred in one form or another in The Netherlands, Belgium, and Oregon, even though some have denied that slippery slopes exist at all.<sup>23</sup>

### *The Logical Slippery Slope*

The logical slippery slope from voluntary euthanasia to non-voluntary euthanasia has been the subject of much debate, with perhaps the clearest case being put forward by Keown<sup>24</sup>, and discussed extensively by Jones<sup>25</sup>, who ultimately accepted a reworked version of Keown's formulation.

The key idea behind the logical slippery slope is that a doctor, in agreeing with a patient with capacity that euthanasia will be a benefit to him or her, can justifiably make a similar judgment for a patient without capacity. In other words, there appears to be no strong reason why a doctor making a judgement about benefit should also not be able to make a judgement based upon imagining what would be a patient's unspoken wishes. One might argue that the initial conditions *require* an autonomous request from the patient, and that this can be demanded as an essential element of the process, but as soon as a doctor uses their will and judgement to form a view that euthanasia will benefit the patient; that is, that death is a better state of affairs for the patient than remaining alive, then it is hard to see why a doctor cannot also use their will and judgement to form a view that euthanasia will similarly benefit a patient without capacity. The law might currently restrain a doctor from acting upon that belief, but some will think it illogical when dealing with a patient without capacity who appears objectively to be in a similar state of suffering to someone with capacity. This is essentially the principle that greases the slope, or as Jones quotes Ramsey as saying, "... the principle behind the wedge hammering it in ...".<sup>26</sup> A doctor presented with two very similar cases of unbearable suffering, for which only one patient can request death, might understandably think the other patient would also request death if he or she were able. Hence the doctor's judgment is really the one that counts, inasmuch as they enable the act; and that judgment may take on proportionally greater significance in a climate where death is broadly accepted as a solution to suffering.

It is usually argued that patient autonomy is important, but if it becomes too important another problem arises, namely that an autonomous request for euthanasia on much broader grounds than unbearable suffering should be respected - for example, a request because someone is 'tired of life'. In other words, if patient autonomy is really what counts, why should suffering of a particular kind and intensity be a necessary requirement for euthanasia? Surely when a patient calls time on their suffering, whatever its nature or extent, that should be enough to trigger a doctor's participation – at least if unfettered autonomy is accepted?

*Either* euthanasia as a benefit *or* patient autonomy may alternately be used to justify non-voluntary euthanasia or euthanasia on request, respectively. Behaviour may even be driven by some degree of arbitrary preference and desire – at the individual level as well as the political – and resort to emphasis on one or the other principle. The different approach of The Netherlands compared with Oregon points to these differences in emphasis. In the former, unbearable pain and suffering have been the main justification for euthanasia, whereas in the latter, individual autonomy and choice take greater precedence (terminality within a given timeframe is required rather than unbearable suffering). But even those systems based upon suffering as a requirement might rely more upon autonomy.

Indeed, some suffering-based regimes might more accurately be re-framed as 'autonomy-based with suffering as a safeguard' regimes. If a jurisdiction leaves the determination of

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<sup>23</sup> For a discussion, see Cook, who notes that some have taken "... the philosophical high ground and respond that slippery slopes either do not exist or are conceptually incoherent." Cook M (2020) Is the 'slippery slope' just a big nothingburger? *BioEdge* (<https://www.bioedge.org/bioethics/the-big-nothingburger-of-slippery-slopes/13329> Accessed 16 Feb 2020).

<sup>24</sup> Keown J (2002) *Euthanasia, Ethics and Public Policy*. Cambridge: Cambridge University Press.

<sup>25</sup> Jones DA (2011) Is There a Logical Slippery Slope from Voluntary to Nonvoluntary Euthanasia? *Kennedy Inst Ethics J* 21(4):379-404.

<sup>26</sup> *Ibid.*

suffering as the justification for PAD entirely up to the patient, as in Canada, the ultimate justification for PAD seems to be autonomy ...<sup>27</sup>

While those opposed to euthanasia have been the first to warn about a logical slippery slope from voluntary to non-voluntary euthanasia, some of the foremost advocates of euthanasia have also tacitly agreed with that logic. Jones quotes Keown, who points out “many leading philosophical advocates of VAE [Voluntary Active Euthanasia], such as Peter Singer and Helga Kuhse, Jonathan Glover and John Harris, also condone NVAE [Non-Voluntary Active Euthanasia]”.<sup>28</sup>

For the suffering patient without capacity, some medical professionals may be so certain of their own wishes were they to suffer similarly that they may even see their actions in administering non-voluntary euthanasia as honouring the patient’s autonomy. In other words, they cannot see that anyone could actually wish to continue living in such a state, and may assume the patient *must* think as they do. Hence, while justification for non-voluntary euthanasia may be primarily based upon discernment of suffering that is common to the patient with capacity and without capacity, it is also informed by the autonomy of the physician in some sense projected onto the patient.

If death as a benefit and respect for autonomy work together in this way, this may explain why on the one hand there are increasing calls for euthanasia of patients with compromised autonomy such as children, dementia patients and the mentally ill, and at the same time pressure to respect the autonomous wishes for euthanasia of those who feel they have a completed life.

Some go further still and claim that acts of non-voluntary euthanasia are in fact not euthanasia at all. It is worth quoting from the Dossier of the *European Institute of Bioethics* on this matter *in extenso*:

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”. What is the difference between the active ending of a person’s life and euthanasia? Does the state of necessity arise out of extreme suffering or the extreme powerlessness of the medical profession who are confronted with this extreme suffering? 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.<sup>29</sup>

In addition to discussion about the link between voluntary and non-voluntary euthanasia in academic discourse, Pollard makes the important observation that the public often makes the connection all too clearly, even if perhaps not entirely aware of how the transition in thinking happens.

Ready proof that the progression of VE [Voluntary Euthanasia] to NVE [Non-Voluntary Euthanasia] has grounds in logic is available whenever euthanasia becomes a topic for public discussion following the media disclosure of some instance of mercy killing. At such times, radio talk-back programs quickly come round to discussing the plight of the senile, elderly people in nursing homes, how their lives are futile, how they, their families and

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<sup>27</sup> 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.

<sup>28</sup> Jones DA (2011) *Op. Cit.*

<sup>29</sup> 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.

the public purse would all experience great relief from their demise, and particularly singled out for comment are those who are irreversibly mentally incompetent. This is heard from those who, shortly before, professed to want only VE, and who, I suspect, do not even realise they have made this subtle but significant mental shift.<sup>30</sup>

### *The Empirical Slippery Slope*

Before considering the evidence for an empirical slippery slope, it is important to revisit definitions of euthanasia to be clear about what might actually constitute a case of non-voluntary euthanasia. Since euthanasia involves the intention to end life, cases of euthanasia include those by act as well as those by omission; that is, those by lethal injection as well as those by the withdrawal of reasonable care with the aim of ending life. Those by lethal injection might involve a concoction of substances to expressly induce death, usually with barbiturates; but death may also be achieved using opiates, where their legitimate use to control pain can instead be translated to an overdose to induce death. In such cases a death reported as due to an increase in pain medication with the intention to hasten death, rather than solely to control pain, is a case of active euthanasia. Why else increase pain medication when pain is already controlled?

When reasonable care such as nutrition and hydration, including where these are artificially administered, is withdrawn with the explicit or implicit intention to hasten death, and the patient is not able to consent, such cases are also non-voluntary euthanasia (by omission). The increasing number of cases of CDS with the intention to end life must also be included as cases of non-voluntary euthanasia when there is no consent. Such cases are more overt when sedation is used to remove the opportunity for consent and nutrition and hydration are concurrently withdrawn. The difficulty with such cases is that there is a legitimate use of sedation as much as there is legitimate withdrawal of food and possibly fluids when death is clearly imminent and the body fails to assimilate any sustenance provided. Sedation should be used judiciously to palliate distressing symptoms, not as part of a strategy to induce death; and similarly, the removal of food and fluids on the grounds of continued use being harmful to the patient is quite different to withdrawal to induce death by the denial of sustenance.

Also included within the definition of non-voluntary euthanasia should be cases of withdrawal of nutrition and hydration from patients with prolonged disorders of consciousness (PDOCs), where consent is clearly impossible. The cause of death will be starvation and dehydration with the intention to end life.

Looking for evidence of a slippery slope from voluntary to non-voluntary euthanasia is particularly difficult because showing such a slide depends upon identifying changes in practice that can be *attributed* to the change in legislation that permits voluntary euthanasia. This would require good quality evidence from before the change as well as after, at the same time as any potential confounders could be accounted for. Such data is thin on the ground. It is also possible to follow the trajectory of changes in the incidence of non-voluntary euthanasia through time after a legislative change to see whether there is a steady increase – if so, this would suggest a slide. Again, data is limited. An alternative approach is to examine the prevalence of non-voluntary euthanasia in legislatures with legal euthanasia compared to those without. This has been attempted<sup>31</sup>, but is problematic because of variations in practice due to cultural and resource factors, as well as difficulty in standardizing the questions asked of medical professionals. Moreover, data obtained in a climate of illegality is unlikely to be as reliable as that obtained within a legal environment, even though that in itself is also made unreliable by poor reporting practices.

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<sup>30</sup> Pollard B (circa 1999) Non-voluntary euthanasia. Occasional paper, Southern Cross Bioethics Institute. See <http://www.bioethics.org.au/Resources/Online%20Articles/Other%20Articles/Non-voluntary%20euthanasia%20in%20Australia%20-%20Brian%20Pollard's%20fourth%20Document.pdf> Accessed 30 Jan 2020.

<sup>31</sup> Lewis P (2007) The Empirical Slippery Slope from Voluntary to Non-Voluntary Euthanasia. *J Law Med Ethics* Spring 197-210.

With these caveats in mind, what do we know about the incidence of non-voluntary euthanasia in legislatures where voluntary euthanasia is permitted?

### *Non-Voluntary Active Euthanasia (NVAE)*

Before considering the majority of cases, it is necessary to review active euthanasia of infants as an obvious example where consent is absent. While it may be argued that these cases are just like any medical treatment of an infant or child, where consent of the parents is normally determinative, it needs to be reiterated that the public debate to convince communities to legalise euthanasia has almost always been about voluntary choice, with a certain type of hard case in mind (adult, sound mind, repeated request, unbearable physical suffering, more than one doctor involved, etc). Anecdotally, the inclusion of infants tends to shock most people, as with the sense of surprise and disturbance they feel when made aware of cases of non-voluntary euthanasia of adults, but with the added layer of the deep protective sense most people have about infants, at least in part because they cannot consent.

In recent research from Austria, where the majority of the public oppose neonatal euthanasia, opposition was found to be greater amongst those under 45, implying that rejection of the idea may rise further in future years.<sup>32</sup> While this may be true of the general public, debate about infant euthanasia has been the subject of serious discussion in academic circles for many years. For example, in a 2013 issue of the *Journal of Medical Ethics*, Giubilini and Minerva articulated the case for the killing of infants on the grounds of their purported lack of moral status, a practice they called after-birth abortion, a euphemism for infanticide.<sup>33</sup> Such killing of disabled as well as healthy infants was met with some degree of support<sup>34</sup> as well as majority opposition.<sup>35,36</sup>

In Holland, euthanasia of infants has been happening for many years. When Verhagen & Sauer first published the Groningen Protocol, 22 cases of infant euthanasia over a seven-year period had been reported to authorities; that is, approximately 3 per year.<sup>37</sup> However, a national survey of neonatologists and death certificate analysis revealed that in fact many more cases were occurring, showing a very high rate of under-reporting.<sup>38</sup> The survey grouped cases of neonatal deaths where there was an explicit intention to hasten death using drugs into two categories – those where the infant was not on life sustaining treatment, and those where the infant was, in which case drugs to end life were used along with the removal of treatment. In the first group, 1% of all infant deaths per year (10 – 15 cases) were active euthanasia. In the second group there were 8%, or 80 – 120 cases per year. In this second group, life was shortened by less than one month in 67% of cases and more than one month in 33% of cases (noting the difficulty in making such a prediction). These are cases of active euthanasia because drugs were used explicitly to end the life of infants who were expected to live for weeks or months. In any case, how long the infants might have been expected to live with or without life-sustaining treatment is irrelevant - these were cases of active euthanasia.

When cases with or without life support are added together, the actual number of cases of active euthanasia of infants in The Netherlands from the 1995 survey was 90 – 135 per year (approximately 9% of all infant deaths per year).

Despite the above, in their 2005 paper, Verhagen and Sauer considered that only about 15 – 20 cases of euthanasia of neonates occurred each year, of which only about 3 per year were reported at that

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<sup>32</sup> Goldnagl L *et al.* (2014) Attitudes among the general Austrian population towards neonatal euthanasia: a survey. *BMC Medical Ethics* 15:74.

<sup>33</sup> Giubilini A & Minerva F (2013) After-birth abortion: why should the baby live? *J Med Ethics* 39(5):261-263.

<sup>34</sup> Singer P (2013) Discussing Infanticide. *J Med Ethics* 39(5):260.

<sup>35</sup> George RP (2013) Infanticide and madness. *J Med Ethics* 39(5):299-301.

<sup>36</sup> Laing JA (2013) Infanticide: a reply to Giubilini and Minerva. *J Med Ethics* 39(5):336-340.

<sup>37</sup> Verhagen AAE & Sauer PJJ (2005) The Groningen Protocol - Euthanasia in Severely Ill Newborns. *New Engl J Med* 352(10):959-962.

<sup>38</sup> van der Heide A *et al.* (1997) Medical end-of-life decisions made for neonates and infants in the Netherlands. *Lancet* 350:251-55.

time.<sup>39</sup> They came to this conclusion because they only considered active euthanasia to have occurred when the infant was not on life-sustaining treatment. Why they excluded the majority of cases where drugs were administered explicitly to end life was not explained.

The 1995 survey was repeated in 2001, 2005, and 2010. The data for 2001 and 2005 was similar to the 1995 data; however, the 2010 survey revealed a huge drop in cases of active euthanasia. Where the total (active euthanasia of infants with and without life support) for 1995, 2001, and 2005 respectively was 9%, 9% and 8%, that for 2010 was 1%.<sup>40</sup> The authors explained this as due to an increase in late term abortion, yet it is unlikely that this alone could account for such a large change in the frequency of neonatal euthanasia. Another possibility is that physicians increasingly saw their actions to end life *not* as euthanasia, given the narrow construal of this term by key figures such as Verhagen.<sup>41</sup> The authors of the 2001, 2005, and 2010 surveys provide an example where a neuromuscular blocking agent was administered to end the life of an infant, yet this was not considered to be euthanasia by the physician involved – even though such agents were used to intentionally end life by respiratory paralysis.

In addition, the 2010 survey revealed a significant drop in the response rate from physicians. Part of the reason for this may be that in 2006 a new national expert committee was established in The Netherlands to ensure reporting of cases where the life of an infant was deliberately terminated. Upon reporting, the committee would decide whether criteria had been met and whether to refer the case for possible prosecution. The establishment of greater scrutiny by such a committee and risk of prosecution may have achieved two things – either far fewer cases of active euthanasia of infants, or a similar number but with greater secrecy and intent to avoid scrutiny. The latter may go some way to explain the drop in response rate in 2010, potentially from physicians who had undertaken active euthanasia and who were concerned about exposure, despite the promised anonymity of the survey.

Even if the figure of 1% for 2010 was accurate, this translates to 10 – 15 cases of active euthanasia of infants in The Netherlands per year, and yet only 2 cases over a 5 year period around 2010 were reported.<sup>42</sup> It is deeply concerning and misleading that some euthanasia activists have used this reported incidence as an accurate estimation of neonatal euthanasia in Holland.<sup>43</sup>

In 2005, Provoost *et al.* undertook similar death certificate research in Belgium, finding that 7% of cases involved the administration of lethal drugs with an explicit intention to end life, despite the practice being illegal.<sup>44</sup> This research involved 17 cases of active euthanasia of infants in Flanders alone per year (1999/2000), and hence the figures for the whole of Belgium would be expected to be higher. This study also incorporated a survey of physicians' attitudes, finding strong support for ending life by lethal injection in such cases.

While there has been limited research in countries where euthanasia is illegal, work by Cuttini *et al.* in the year 2000 surveyed physicians in neonatal intensive care units in seven European countries. The percentage of physicians who had ever used drugs "with the purpose of ending life" were as follows: France (73), The Netherlands (42), Germany (4), UK (4), Italy (2), Spain (2), and Sweden (2).<sup>45</sup> The low

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<sup>39</sup> Verhagen AAE & Sauer PJJ (2005) *Op. Cit.*

<sup>40</sup> ten 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.

<sup>41</sup> In any case, non-voluntary euthanasia of adults in Holland is not termed euthanasia, but instead 'ending of life without patient's explicit request'.

<sup>42</sup> This suggests a reporting rate of less than 5%; see Verhagen AAE (2013) The Groningen Protocol for newborn euthanasia; which way did the slippery slope tilt? *J Med Ethics* 39(5):293-295.

<sup>43</sup> In the public euthanasia debate in Australia in 2015, high profile euthanasia advocate Andrew Denton stated, "I interviewed the protocol author, Dr Eduard Verhagen, Paediatrics Department, University Medical Centre Groningen. He told me that since just before 2007 the lives of only two neonates had been ended under the Groningen Protocol." See <https://theconversation.com/full-response-from-andrew-denton-50600> Accessed 13 Jan 2020. This statement was put forward as evidence that neonatal euthanasia was very rare in The Netherlands, and claims about much higher numbers were false and misleading.

<sup>44</sup> Provoost V *et al.* (2005) Medical end-of-life decisions in neonates and infants in Flanders. *Lancet* 365:1315-1320.

<sup>45</sup> Cuttini M *et al.* (2000) End-of-life decisions in neonatal intensive care: physicians' self-reported practices in seven European countries. *Lancet* 355:2112-2118.

rates in countries where euthanasia is illegal make sense when compared to The Netherlands, but France is an exception. Since the year 2000, there appears to have been a significant change in France, potentially due to legislative changes and new regulatory guidance. Active euthanasia of neonates has instead now become the exception<sup>46</sup>, which appears to have been welcomed by medical staff:

All the most senior doctors expressed their relief. 'Ending life was no longer possible for me', said one. Another confided: 'I have fewer nightmares. There is more satisfaction in work well done.' Another added that the purpose changed: 'When we stop intensive care, our intention is no longer to end life but to provide palliative care and control pain, even at the risk of hastening death'.<sup>47</sup>

This is an example of a cultural shift in neonatal care unlike what has taken place in countries like The Netherlands and Belgium, both of which have a culture that endorses neonatal euthanasia.

While infant euthanasia is undoubtedly happening, most prominently in Belgium and The Netherlands, its numbers are small when compared with the numbers of cases of NVAE of adults. In The Netherlands, official reports began in 1990. The first two reports for 1990 and 1995 revealed that 0.8% and 0.7% of all deaths respectively, resulted from 'ending of life without patient's explicit request'.<sup>48</sup> This translates to 1030 NVAE deaths in 1990 and 948 in 1995.<sup>49</sup> However, this is an underestimation; in 1990 and 1995 respectively, there were also 1350 and 1896 deaths in which opioids were used with the explicit intention to end life (within the separate category, 'opioids in large doses'), a significant proportion of which almost certainly occurred without request. Hendin estimates that for the year 1995 "Of the more than 6000 deaths in which physicians admit to having actively and intentionally intervened to cause death, 40 percent involved no explicit request from the patient for them to do so."<sup>50</sup> This would suggest that there were actually at least 2400 cases of NVAE in The Netherlands in 1995, rather than the 948 figure cited above.

Moreover, when the reporting rate for voluntary euthanasia was around 50% from 1995 through to 2002<sup>51</sup>, it is likely - perhaps even more so given its illegal nature - that there would be an even lower rate of reporting of NVAE. Hence, the real rate of NVAE may well have been considerably higher than 2400 per year. The reporting rate has since improved and was 77% in 2010.<sup>52</sup>

Subsequent reports, done approximately every 5 years, reveal a decline in cases within the limited category 'ending of life without explicit patient request' – 0.7% for 2001, 0.4% for 2005, 0.2% for 2010 and 0.3% for 2015.<sup>53,54,55</sup> Unfortunately, as Hendin noted for the 2001 report, "This time, however, the Dutch investigators did not report the number of cases in which patients who had not consented were given pain medication by physicians with the explicit intention of ending their lives."<sup>56</sup> This appears also to be true for 2005, 2010 and 2015, making it even harder to estimate the true number of cases of NVAE in these years.

However, it may be possible to explain, at least in part, the apparent decline in cases of NVAE in more recent years, even without specific knowledge about the proportion of cases involving high doses of

<sup>46</sup> Garel *et al.* (2011) Ethically complex decisions in the neonatal intensive care unit: impact of the new French legislation on attitudes and practices of physicians and nurses. *J Med Ethics* 37(4):240-243.

<sup>47</sup> *Ibid.*

<sup>48</sup> 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.

<sup>49</sup> *Ibid.*

<sup>50</sup> Hendin H (2002) The Dutch Experience. In: *The Case against Assisted Suicide. For the Right to End-of-Life Care*. Eds Foley K & Hendin H, John Hopkins University Press, Baltimore, 105.

<sup>51</sup> Sheldon T (2003) Only half of Dutch doctors report euthanasia, report says. *BMJ* 326:1164.

<sup>52</sup> Onwuteaka-Philipsen BD *et al.* (2012) Trends in end-of-life practices before and after the enactment of the euthanasia law in the Netherlands from 1990 to 2010: a repeated cross-sectional survey. *Lancet* 380:908-915.

<sup>53</sup> *Ibid.*

<sup>54</sup> van der Heide A *et al.* (2007) End-of-Life Practices in the Netherlands under the Euthanasia Act. *New Engl J Med* 356(19):1957-1965.

<sup>55</sup> 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.

<sup>56</sup> Hendin H (2002) *Op. Cit.*, 109.

opioids to intentionally end life without request, if we note that from 2001, the relevant category ‘opioids in large doses’ was renamed ‘intensified alleviation of symptoms’. Whereas for 1990 and 1995, the percentages of all deaths within this category were 18.8% and 19.1% respectively, they climbed over the next few reports to 20.1% for 2001, 24.7% for 2005, and 36.4% for 2010, before leveling out to 35.8% for 2015.<sup>57</sup> Such large increases could easily allow for many hidden cases of NVAE using opioid overdose, enough to cover the decline within the overt category ‘ending of life without explicit patient request’. Furthermore, renaming the opioid overdose category ‘intensified alleviation of symptoms’ not only masks the use of opioids, but also implies an intention that goes beyond symptom control.

It would not be inconceivable that instead of a decline, there has instead been a steady increase in NVAE in The Netherlands, especially given a progressively developing euthanasia culture and the propensity to define euthanasia so narrowly. Doctors may be more inclined to interpret their actions *not* as euthanasia but rather as symptom treatment to avoid the reporting process, even if there was an intention to hasten death. Moreover, concern about international scrutiny regarding a slide towards NVAE could influence reporting behaviour. In a 2009 pilot study, Draper *et al.* concluded that 28% of UK doctors would “not be consistently honest, or even would be consistently dishonest” about end of life decisions.<sup>58</sup> Dutch doctors may be no different to their UK counterparts, regardless of the legal environment.

In the end, there is no way to be certain about the extent of NVAE in the Netherlands, because there is insufficient research of a standard necessary to permit such a determination. Nevertheless, what evidence does exist suggests that the practice is extensive.

The other legislature in which some data exists is Belgium, but before considering the Belgian data it is worth briefly looking at a study from Australia, undertaken in 1997, where it was claimed there was a 5 times higher rate of NVAE there compared with The Netherlands (3.5% versus 0.7%).<sup>59</sup> If accurate, this study could be interpreted as evidence that the legal regime in The Netherlands is more effective in reducing unwanted NVAE than the illegal one in Australia, a claim that has been used by supporters of euthanasia legalisation.<sup>60</sup> However, the Australian survey has been strongly criticised for conflating categories to yield an inaccurate estimate of euthanasia without explicit request.<sup>61</sup> Amarasekara agreed with public comments made at the time, which bluntly described the error as “a serious obfuscation”.<sup>62</sup> When the survey was corrected and used in the UK, the rate was 0.33%, half of that in The Netherlands and one tenth of that in the Australian survey – noting the limitations of the Dutch data as described above.<sup>63</sup> Continued use of the Australian data to argue against a slippery slope to non-voluntary euthanasia in countries where voluntary euthanasia is legal is therefore without justification.

In Belgium, the rates of ‘hastening of death without explicit request from the patient’ are higher than in the Netherlands. In 1998, the rate was 3.2%, which translated to 1796 deaths.<sup>64</sup> Similar surveys took place in 2001, 2007, and 2013, in which the rates were 1.5%, 1.8%, and 1.7%, respectively.<sup>65,66</sup> Belgium has a worse problem with under-reporting when compared with The Netherlands.<sup>67</sup>

<sup>57</sup> van der Heide A *et al.* (2017) *Op. Cit.*

<sup>58</sup> Draper H *et al.* (2009) Reporting end-of-life practice: can we trust doctors to be honest? *Palliative Medicine* 23:673–674.

<sup>59</sup> Kuhse H *et al.* (1997) End-of-life decisions in Australian medical practice. *Med J Aust* 166:191-196.

<sup>60</sup> For an account of such claims, see Lewis P (2007) *Op. Cit.*

<sup>61</sup> In response to Kuhse H *et al.* (1997) *Op. Cit.*, see Letters to the Editor by Fisher A *et al.*, McKay DS, and Davies LM, *Med J Aust* 166:506-507.

<sup>62</sup> Amarasekara K (1997). Euthanasia and the quality of legislative safeguards. *Monash University Law Review* 23(1):1-42.

<sup>63</sup> Seale C (2006) National survey of end-of-life decisions made by UK medical practitioners. *Palliative Medicine* 20:3-10.

<sup>64</sup> Deliens L *et al.* (2000) End-of-life decisions in medical practice in Flanders, Belgium: a nationwide survey *Lancet* 356:1806-1811.

<sup>65</sup> Bilsen J *et al.* (2009) Medical End-of-Life Practices under the Euthanasia Law in Belgium. *N Engl J Med* 361(11):1119-1121.

<sup>66</sup> Chambaere K *et al.* (2015) Recent Trends in Euthanasia and Other End-of-Life Practices in Belgium. *N Engl J Med* 372(12):1179-1181.

<sup>67</sup> Only about 50% of cases are reported; see Smets T *et al.* (2010) Reporting of euthanasia in medical practice in Flanders, Belgium: cross sectional analysis of reported and unreported cases. *BMJ* 341:c5174.

In 1998, there were a further 2966 deaths (5.3% of all deaths) in which opioids were used with an intention to hasten death along with the intention to alleviate pain and other symptoms ('intensified alleviation of pain and other symptoms').<sup>68</sup> Unfortunately, there was no breakdown to show how many of such cases occurred without consent. Moreover, in addition to this gap in the data, in later surveys this category no longer even allowed a breakdown to identify intention to hasten death. The percentage of cases in which opioids were used increased from 1998 to 2007 before declining in 2013 (18.4% in 1998; 22% in 2001, 26.7% in 2007; and 24.2% in 2013).<sup>69</sup> If this increase involved, as seems a reasonable assumption, a proportionate increase in cases intended to hasten death, some of which would almost certainly have occurred without consent, the number of cases of NVAE via intensified pain control may have been increasing, at least up until the 2007 survey.

The idea that opioids for pain and symptom control would also be used to end life, specifically without consent, is reinforced by a different type of study in which opioids were used in all but one of 13 cases that were chosen specifically because death was intentionally hastened without explicit consent.<sup>70</sup> It is surely not without significance that opioid overdose was the means of inducing death in a group of cases chosen specifically because they involved the intention to end life without consent. Moreover, it is already known that Belgian doctors routinely misclassify such cases as *not* being euthanasia<sup>71,72</sup>, lending support to the likelihood that many cases of NVAE are occurring in Belgium via opioid overdose and yet are not recorded as such.

In a 2010 study published in the *Canadian Medical Association Journal (CMAJ)* by Chambaere *et al.* that involved a representative sample of Belgian doctors who had administered drugs with the explicit intention to end life (that is, they undertook active euthanasia), 32% of cases were without an explicit request from the patient.<sup>73</sup> Over 95% of these involved opioids. Hence, there were clearly many cases where death had been intentionally caused by opioid overdose under the umbrella of intensified alleviation of pain, yet without consent.<sup>74</sup>

In the same issue of *CMAJ*, another paper was published that investigated the involvement of Belgian nurses with the 'administration of life ending drugs with explicit intention of ending the patients life'.<sup>75</sup> The researchers found that 120 of 248 nurses (48%) involved in such cases had done so without an explicit request from the patient. That is, nearly half of cases constituted NVAE. While this study cannot tell us the actual number of cases of NVAE per year, what it does reveal is that there seem to be approximately the same number as voluntary cases. The authors were careful to define only those cases where there was an explicit request as euthanasia. Those without an explicit request were simply not considered euthanasia, despite there being a clear intention to end life by a lethal dose of drugs. This method of classification, as in the survey work described above from both The Netherlands and Belgium, muddies the waters about the true incidence of active euthanasia in those countries and in doing so also masks the incidence of NVAE. Whether someone requests a lethal injection or is

<sup>68</sup> Deliens L *et al.* (2000) *Op. Cit.*

<sup>69</sup> Smets T *et al.* (2010) *Op. Cit.*

<sup>70</sup> Meeussen K *et al.* (2010) 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* 10:186.

<sup>71</sup> Smets T *et al.* (2010) *Op. Cit.*

<sup>72</sup> Cohen-Almagor R (2013) First do no harm: pressing concerns regarding euthanasia in Belgium. *Int J Law Psychiatry* 36:515–521.

<sup>73</sup> Chambaere K *et al.* (2010a) Physician-assisted deaths under the euthanasia law in Belgium: a population-based survey. *Can Med Assoc J* 182(9):895-901.

<sup>74</sup> In 2014, Chambaere *et al.* revisited the 32% of cases of non-voluntary active euthanasia (66 in total) and argued that such cases did not really fit the category of non-voluntary euthanasia, either because the patients had previously expressed a wish to die, or because the doses used had been in line with symptom control (Chambaere K *et al.* (2014) Characteristics of Belgian "life-ending acts without explicit patient request": a large-scale death certificate survey revisited. *Can Med Assoc J Open* 2(4):E262-E267.) However, this is unconvincing, not only because patients may express a wish to die at one stage or another that is either a call for help and/or not maintained, but also because the cases were *specifically chosen in the first place* because the doctors involved said they administered drugs with the explicit intention to end life. Hence the cases were clearly directed to ending life rather than symptom control. If they had actually been cases of symptom control alone, then there would have been no explicit intention to end life, but this was not the case.

<sup>75</sup> Inghelbrecht E *et al.* (2010) The role of nurses in physician-assisted deaths in Belgium. *Can Med Assoc J* 182(9):905-910.



unable to do so, in either case life is intentionally ended using drugs, which constitutes active euthanasia.<sup>76</sup>

To summarise this section, while the precise numbers of cases of NVAE in Belgium and The Netherlands cannot be known at this stage - partly because of a failure on the part of Dutch and Belgian investigators to properly categorise actions as euthanasia, as well as that of doctors to understand or accurately report their actions – there are almost certainly large numbers, at least in the thousands each year in each country. Investigating and reporting remains so poor that trends cannot be identified either; however, there are increases in other end-of-life categories within which increasing numbers of cases of NVAE could be occurring yet remain masked.

### *Non-Voluntary Euthanasia by Omission*

Euthanasia by omission is a more difficult phenomenon to study because it relies upon distinguishing between the legitimate versus illegitimate withholding or withdrawing of treatment – divining intention is sometimes difficult, and complex medical and personal judgements will also be made about whether treatment is futile or overly burdensome and disproportionate to benefit. A health professional could decide upon non-treatment as a means of intentionally bringing a patient's life to an end, or they could decide that futile or overly burdensome treatment that is disproportionate to any benefit should be foregone without any intention to end the patient's life.

One area of particular controversy concerns the administration of artificial nutrition and hydration (ANH), sometimes referred to as clinically assisted nutrition and hydration (CANH).<sup>77</sup> In recent years CANH has been interpreted as medical treatment rather than the provision of reasonable care, making it easier to deny to patients. This is an important issue, inasmuch as forgoing CANH has become part of a particular regime sometimes intended to end the lives of patients. When coupled with heavy sedation that continues to an intended death, continuous deep sedation (CDS) has become one, perhaps the primary, means of euthanasia by omission. There may even be an incentive to use CDS to end life rather than active euthanasia, because of moral concerns about participation in active euthanasia, as well as the perception that CDS is more 'natural'<sup>78</sup>; but also because CDS does not have the regulatory oversight required of active euthanasia (even though, as previously noted, many doctors do not report cases of active euthanasia, as well as many misunderstanding what constitutes such cases).

If data about NVAE is hard to come by, it is even harder to find for non-voluntary euthanasia by omission, but some exists in earlier reports. When it comes to the specific case of CDS, in more recent years there is some reliable evidence about overall incidence, but the question of consent is only infrequently addressed.

In the first *Remmelink Report* on euthanasia and other end of life decisions from The Netherlands in 1991, based on 1990 data and published in *The Lancet* by van der Maas *et al.*, CDS was not addressed, but there were 8750 cases without patient request, in which treatment was withdrawn or withheld with an implicit (4750) or explicit (4000) intention to terminate life.<sup>79</sup> While detail about these cases is lacking, the evidence suggests that in 1990, cases of explicit non-voluntary euthanasia by omission outstripped cases coded as 'ending of life without patient's explicit request' by 4 to 1, and if the

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<sup>76</sup> Cohen-Almagor R (2015) First do no harm: intentionally shortening lives of patients without their explicit request in Belgium. *J Med Ethics* 41(8):625-629.

<sup>77</sup> Pike GK (2019) The Provision of Nutrition and Hydration to Vulnerable Patients: An Analysis of the Clinical and Ethical Issues. See <https://bioscentre.org/articles/the-provision-of-nutrition-and-hydration-to-vulnerable-patients-an-analysis-of-the-clinical-and-ethical-issues/> Accessed 7 Jan 2020.

<sup>78</sup> Raus K *et al.* (2012) Continuous deep sedation at the end of life and the 'Natural Death' hypothesis. *Bioethics* 26(6):329–336.

<sup>79</sup> van der Maas PJ *et al.* (1991) Euthanasia and other medical decisions concerning the end of life. *The Lancet* 338(8768):669-674.

implicit intention cases are included, by at least 8 to 1.<sup>80</sup> To reiterate, these 8750 cases are those in which there was an implicit or explicit intention to end the life of a patient without consent, and hence constitute cases of euthanasia; more specifically, non-voluntary euthanasia by omission.

In the next *Rommelink Report* in 1995, whereas cases of treatment withholding or withdrawal with the intention to end life were recorded (18071 in 1995<sup>81</sup> compared with 13506 in 1990<sup>82,83</sup>), no breakdown was provided by patient request, making determination of the number of cases of non-voluntary euthanasia by omission not possible. However, if the percentage of those without patient request was approximately the same as in 1990, the number would be in the vicinity of 11700 for 1995 (ie 8.6% of all deaths).

In subsequent years, in the category of withholding or withdrawing treatment, there was no breakdown either by intention to end life or by patient request, so the incidence of non-voluntary euthanasia by omission cannot be determined from the surveys.<sup>84,85</sup>

The situation in Belgium is not dissimilar. Data for 1998 reveal that in 15.7% of all cases examined, treatment was forgone; that is 9218 deaths. For 5324 of these, there was an implicit or explicit intention to end life, and for 89% of these, there was no explicit request from the patient. Therefore, there were 4738 cases of non-voluntary euthanasia by omission (8.4% of all deaths).<sup>86</sup> In subsequent surveys in 2001, 2007 and 2013, within the category of forgoing treatment, also termed a non-treatment decision, no breakdown to show intention to end life was provided, so the incidence of non-voluntary euthanasia by omission in Belgium for these years cannot be determined from the surveys alone.<sup>87,88,89</sup>

In the Dutch surveys, a category for CDS was only included from 2005 onwards. The incidence increased steadily from 8.2% of all deaths in that year to 12.3% in 2010 and 18.3% in 2015.<sup>90</sup> In Belgium, the figures were 8.2% in 2001, 14.5% in 2007, and 12% in 2013. Unfortunately, neither the Dutch nor Belgian surveys provide a breakdown by intention to end life; however, a reasonable case can be made that when deep sedation is initiated and intended to continue until death, especially when CANH is denied (either considered as a non-treatment decision or as the denial of reasonable care), at the very least there is an implicit intention to end life, if not an explicit one. Belgian doctors and nurses see CDS as intentionally hastening death, and often use the term ‘slow euthanasia’ to describe it.<sup>91,92,93</sup> Moreover, some ethicists have argued that in many cases of CDS, if not most, it is implicit in the practice that death is intentionally hastened, in which case it is euthanasia.<sup>94,95</sup> Battin has further argued that autonomy “cannot be honoured in decisions to use terminal sedation”, mainly because of pain at the time of decision making.<sup>96</sup> Moreover, even when pain does not obscure

<sup>80</sup> Fleming JI (1992) Euthanasia, The Netherlands, and Slippery Slopes. *Bioethics Research Notes Occasional Paper No.1*, See <http://www.bioethics.org.au/Resources/Online%20Articles/Other%20Articles/Euthanasia%20the%20netherlands%20and%20Slippery%20slopes.pdf> Accessed 13 Dec 2020.

<sup>81</sup> van der Maas PJ *et al.* (1996) *Op. Cit.*

<sup>82</sup> van der Maas PJ *et al.* (1991) *Op. Cit.*

<sup>83</sup> Fleming JI (1992) *Op. Cit.*

<sup>84</sup> Onwuteaka-Philipsen BD *et al.* (2012) *Op. Cit.*

<sup>85</sup> van der Heide A *et al.* (2017) *Op. Cit.*

<sup>86</sup> Deliens L *et al.* (2000) *Op. Cit.*

<sup>87</sup> Bilsen J *et al.* (2009) *Op. Cit.*

<sup>88</sup> Chambaere K *et al.* (2010b) Differences in Performance of Euthanasia and Continuous Deep Sedation by French- and Dutch-Speaking Physicians in Brussels, Belgium. *J Pain Sympt Management* 39(2):e5-e7.

<sup>89</sup> Chambaere K *et al.* (2015) *Op. Cit.*

<sup>90</sup> van der Heide A *et al.* (2017) *Op. Cit.*

<sup>91</sup> Inghelbrecht E *et al.* (2010) *Op. Cit.*

<sup>92</sup> Sercu M *et al.* (2014) Belgian General Practitioners’ Perspectives on the Use of Palliative Sedation in End-of-Life Home Care: A Qualitative Study. *J Pain Sympt Management* 47(6):1054-1063.

<sup>93</sup> Anquetin M *et al.* (2012) Similarities and differences between continuous sedation until death and euthanasia – professional caregivers’ attitudes and experiences: A focus group study. *Palliative Medicine* 27(6):553-561.

<sup>94</sup> Sulmasy DP (2018) Sedation and care at the end of life. *Theoretical Medicine and Bioethics* 39:171–180.

<sup>95</sup> Battin MP (2008) Terminal Sedation: Pulling the Sheet over Our Eyes. *Hastings Center Report* 38(5):27-30.

<sup>96</sup> *Ibid.*

decision-making, characterising CDS as merely palliative sedation further obscures for the patient the reality of what he or she is deciding upon.

... the patient cannot consent to the really significant decision – whether his or her life shall be ended now. Autonomy is therefore undercut whether the patient's capacity for reflection is impaired by severe pain or not.<sup>97</sup>

In a recent study from Switzerland, the incidence of CDS was found to have increased fourfold from 2001 to 2013 (6.7% to 24.5%). The proportion in which there was an intention to hasten death more than doubled (26.7% in 2001 to 54.5% in 2013); however, the study did not investigate patient consent.<sup>98</sup>

The absence of data in the surveys about an explicit patient request or consent with regard to CDS is problematic as it makes determining the incidence of non-voluntary euthanasia by omission within this category of end-of-life decisions impossible. Nevertheless, despite deficiencies in the data regarding CDS in the surveys described above, there are several other studies that can provide some useful information.

In a 2007 Belgian study, in 17% of CDS cases an intention to hasten death was reported, a much lower figure than that revealed from the earlier surveys in the category of forgoing treatment; however, in the same Belgian study, there was no patient consent in 70% of all CDS cases.<sup>99</sup> Similarly, Rys *et al.* found that about 66% of patients were either incompetent or not fully competent, and could therefore not consent - intention to hasten death was not examined.<sup>100</sup>

In contrast to CDS in Belgium, in The Netherlands at a similar time (2004), a much higher incidence of intention or co-intention to hasten death via CDS was found (64%).<sup>101</sup> Furthermore, while sedation was *discussed* with 59% of patients, CANH was discussed with only 34%. No indication about specific consent by the patient to either of these was provided, simply that the matter was discussed.

The use of CDS in minors has received less attention, but in a Belgian study using 2007/2008 data, CDS was used in 21.8% of all deaths.<sup>102</sup> In 23.5% of these cases there was an explicit intention or co-intention to hasten death. Even though 28% of the patients were over the age of 12, there appears to have been no attempt to engage the children in the decision-making process.

To summarise this section, the evidence (as limited as it is) reveals that an intention to hasten death, whether by treatment withdrawal or CDS, results in many thousands of cases of euthanasia by omission each year in The Netherlands and Belgium. A significant percentage of these, between about 30% and 80%, have occurred without the consent of the patient. It is not possible to put an actual figure on the incidence in recent years, but if earlier reports are indicative, it is more than likely that non-voluntary euthanasia by omission outstrips NVAE many times over.

### *Prolonged Disorders of Consciousness (PDOCs)*

One more group of patients whose lives may be intentionally ended, by definition without their consent, are those with a PDOC - those in a minimally conscious state (MCS) and those in a vegetative

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<sup>97</sup> *Ibid.*

<sup>98</sup> Ziegler S *et al.* (2018) Continuous Deep Sedation Until Death - a Swiss Death Certificate Study. *J Gen Intern Med* 33(7):1052-1059.

<sup>99</sup> Chambaere K *et al.* (2010c) Continuous Deep Sedation Until Death in Belgium: A Nationwide Survey. *Arch Intern Med* 170(5):490-493.

<sup>100</sup> Rys S *et al.* (2014) The Practice of Continuous Sedation Until Death in Nursing Homes in Flanders, Belgium: A Nationwide Study. *J Am Geriatr Soc* 62:1869-1876.

<sup>101</sup> Rietjens JAC *et al.* (2004) Physician Reports of Terminal Sedation without Hydration or Nutrition for Patients Nearing Death in the Netherlands. *Arch Intern Med* 141:178-185.

<sup>102</sup> Pousset G *et al.* (2011a) Continuous Deep Sedation at the End of Life of Children in Flanders, Belgium. *J Pain Sympt Management* 41(2):449-455.

state (VS). The term VS remains in common use despite its connotations. A better term is ‘unresponsive wakefulness syndrome’.<sup>103</sup>

Patients with a PDOC have experienced a traumatic or non-traumatic brain injury and are only able to receive sustenance via CANH. They are not imminently dying and often live for many years, and sometimes decades, although some patients spontaneously regain consciousness. If a decision is made to remove CANH, the immediate cause of death will be dehydration and starvation. Such removal constitutes non-voluntary euthanasia by omission.

The prevalence of patients with a PDOC is not entirely clear, but a combined figure for the UK of 24,000 has been cited.<sup>104</sup>

More detail about patients with PDOCs has been published elsewhere<sup>105</sup>, and it is clear that there is much to learn.

When problems with misdiagnosis are considered together with new findings on the course of natural recovery, and the development of promising interventions, what was once considered true of patients with VS and MCS is now in a state of significant reappraisal. Patients may be more aware than previously thought. They may recover to a greater extent than previously thought. And there may be new treatments that can offer a significant chance of improvement.<sup>106</sup>

The point with respect to the focus of this paper is that with the outcome of cases like Tony Bland in the UK<sup>107</sup> and Terry Schiavo in the US<sup>108</sup>, and the recent UK decision to make CANH removal much easier by no longer requiring involvement of the Court of Protection<sup>109</sup>, the climate has significantly shifted to one in which euthanasia by omission of patients with PDOCs will be more straightforward and likely to be more common. It remains to be seen how the new paradigm for the treatment of PDOC patients in the UK will impact the broader debate about euthanasia and assisted suicide in that country and elsewhere.

### **Euthanasia when Capacity is Compromised**

The assessment of capacity can be a complex task, and advice from the GMC makes it clear that capacity is not simply a binary phenomenon. Capacity may wax and wane and it may be sufficient for some decisions but not others, particularly those with grave and/or irreversible consequences. And particular expertise - potentially legal as well as medical - is required to make such important judgments.

There are three groups of patients for whom questions of capacity are particularly fraught, and who are the focus of the leading edge of debate about euthanasia and assisted suicide. These groups are minors, patients with dementia (a rapidly growing group), and psychiatric patients. Debate and disagreement about euthanasia and/or assisted suicide for those in these categories has often been intense. To what extent they are able to make a free choice to end their lives is the crux of the disagreement; but in any case, despite the debate, patients in these groups are already being euthanased.

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<sup>103</sup> Giacino JT *et al.* (2018) Comprehensive Systematic Review Update Summary: Disorders of Consciousness. *Arch Physical Med & Rehab* 99:1710-1719.

<sup>104</sup>Berg S (2016) Permanent vegetative state: A family's agony. *BBC News* See <https://www.bbc.com/news/magazine-37444379> Accessed 1 March 2019.

<sup>105</sup>Pike GK (2019) *Op. Cit.*

<sup>106</sup> *Ibid.* p33

<sup>107</sup> UK House of Lords Judgement. *Airedale NHS Trust v Bland* [1993] AC 789 (HL).

<sup>108</sup> Hook CC & Mueller PS (2005) The Terri Schiavo Saga: The Making of a Tragedy and Lessons Learned. *Mayo Clin Proc* 80(11):1449-1460.

<sup>109</sup> See <https://www.supremecourt.uk/cases/docs/uksc-2017-0202-judgment.pdf> Accessed 19 October 2018.

## Minors

From 2002, Dutch law permitted euthanasia of minors over the age of 12 under specific conditions; hence capacity was deemed to be restricted on the basis of a specific age. In contrast, when Belgian law permitted the euthanasia of minors in 2014, amidst widespread national and international debate, a multidisciplinary team was charged with the task of determining whether a child of *any age* had the capacity for discernment.<sup>110</sup> It has been argued that this could lead to “arbitrary interpretations by different physicians, psychologists and psychiatrists.”<sup>111</sup> Others were concerned that “children lack the wisdom and experience requisite to make a sound choice about a decision of such magnitude”.<sup>112</sup> The Belgian law also raised questions about why a child might be capable of choosing euthanasia, but “not be capable of actively participating as an “adult” in society”.<sup>113</sup> In any case, the debate within ethics circles continues, even if as far back as 2009, 69% of Belgian physicians favoured a legal change to extend euthanasia to minors.<sup>114</sup>

In The Netherlands from 2005 to 2018, official reports indicate that only 14 children between the ages of 12 and 18 were actively euthanased; that is, about 1 per year.<sup>115</sup> 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).<sup>116</sup> 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 in 2001, of children aged 1 to 17, 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).<sup>117</sup> Importantly, another 15 children per year (2.0%) were actively euthanased with no specific request from the child, but instead one from the parents. These figures from 2001 are unlikely to have changed dramatically in subsequent years leading up to 2014, so it is almost certain that the reporting rate is very low, as is also true for cases of infant euthanasia in Holland.

Additionally, the death certificate study in 2001 occurred before the law changed to permit euthanasia of minors, hence illegal euthanasia of minors (older or younger than 12) was happening. Despite the absence of death certificate research since 2001, it would be reasonable to expect that with legal permission from 2002 onwards, in accord with increases in cases of adult euthanasia in The Netherlands, those of minors would have increased as well. Moreover, it would not be unreasonable to expect that if some doctors saw fit to act illegally before the legal change of 2002, they may likewise have acted illegally after – whether by continuing to euthanase children under the age of 12, or perhaps relaxing consent requirements for children over 12, or in some other way.

It is problematic that prominent researchers in the field argue that euthanasia of minors is very rare in Holland<sup>118</sup>, basing their claim upon 5 cases reported over a 10 year period, when it is more than likely that the real figure is many times higher. Moreover, if cases without request are included, the total number of cases of active euthanasia would be at least an order of magnitude higher than claimed from official reports.

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

<sup>110</sup> Dan B *et al.* (2014) Self-requested euthanasia for children in Belgium. *Lancet* 383:671-672.

<sup>111</sup> Cuman G & Gastmans C (2017) Minors and euthanasia: a systematic review of argument-based ethics literature. *Eur J Pediatr* 176:837–847.

<sup>112</sup> Siegel AM *et al.* (2014) Letters (In Reply) Euthanasia for Minors in Belgium. *JAMA* 312(12):1259. See also Siegel AM *et al.* (2014) Pediatric Euthanasia in Belgium: Disturbing Developments. *JAMA* 311(19):1963-1964.

<sup>113</sup> Cuman G & Gastmans C (2017) *Op. Cit.*

<sup>114</sup> Pousset G (2011b) Attitudes and practices of physicians regarding physician-assisted dying in minors. *Arch Dis Child* 96:948–953.

<sup>115</sup> 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.

<sup>116</sup> Rietjens JAC *et al.* (2014) Letters (To the Editor) Euthanasia for Minors in Belgium. *JAMA* 312(12):1258-1259.

<sup>117</sup> Vrakking AM *et al.* (2005) Medical End-of-Life Decisions for Children in the Netherlands. *Arch Pediatr Adolesc Med* 159:802-809.

<sup>118</sup> Rietjens JAC *et al.* (2014) *Op. Cit.*

lethal drugs) without an explicit request from the child, amounting to about 10 per year in Flanders alone.<sup>119</sup> This figure is nearly 4 times the rate in The Netherlands (7.9% v. 2.0%), albeit at different times. Again, this occurred at a time when euthanasia of minors was illegal in Belgium.

There is very limited evidence about the extent of euthanasia of minors by omission. In Belgium in 2007/2008, Pousset *et al.* found that in 6.7% of all deaths in minors in which treatment was forgone, there was an intention to hasten death.<sup>120</sup> This translates to approximately 8 cases per year. As noted earlier, CDS in minors in Belgium is a much larger category, but only about one quarter of such cases involved an intention or co-intention to hasten death.<sup>121</sup> CDS in Holland in minors has not been studied in any detail, but approximately 24% of Dutch pediatricians had used CDS for a child who was also concurrently denied CANH.<sup>122</sup>

In summary, just as for cases involving infants in Holland and Belgium, there are many more cases of active euthanasia of minors than those officially reported. Cases of active euthanasia when the child is very young cannot involve consent, and even for older children who may be able to *assent*, whether they can grasp the significance of all that their decision means is highly questionable. While the data does not exist in recent years, that from the 2000s in Holland and Belgium indicate that cases of NVAE occur far more frequently than the already problematic cases with request. To these cases must be added cases of euthanasia by omission, whether forgoing of treatment with intent to hasten death, or CDS with denial of CANH. The numbers in this category are not known for either Holland or Belgium.

### *Dementia Patients*

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.<sup>123</sup>

Euthanasia of dementia patients is deeply controversial, primarily because at the time of euthanasia there is a significant question mark over the ability of the patient to provide consent, depending on the severity of the condition.<sup>124</sup> 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.<sup>125</sup> The woman had previously expressed a wish to be euthanased at the time of her choice, but when the doctor and family decided the time had come, she was deemed unable to state her wishes and yet resisted the lethal injection.<sup>126</sup> Assistance from family members was required to complete the act.<sup>127</sup>

Such is the dilemma of euthanasia and dementia – a free choice does not necessarily exist with dementia, and certainly not with advanced dementia, but accepting a prior wish expressed under different circumstances is not straightforward either.

<sup>119</sup> 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.

<sup>120</sup> *Ibid.*

<sup>121</sup> Pousset G *et al.* (2011a) *Op. Cit.*

<sup>122</sup> Vrakking AM *et al.* (2005) *Op. Cit.*

<sup>123</sup> 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.

<sup>124</sup> Menzel PT & Steinbock B (2013) Advance Directives, Dementia, and Physician-Assisted Death. *J Law Med Ethics* 41(2):484-500.

<sup>125</sup> In April 2020, the Dutch Supreme Court ruled the case permissible. See <https://www.bbc.com/news/world-europe-52367644>. Accessed 23 April 2020.

<sup>126</sup> 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.

<sup>127</sup> 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.

Along with terminal illness, defined as prognosis of death within six months, *contemporary competence* is regarded as an important safeguard against mistake and abuse, arguably the strongest objections to legalizing PAD.<sup>128</sup> [emphasis added]

In The Netherlands an advance euthanasia directive (AED) can be made when the dementia patient still has capacity. Such a directive would then be enacted when the patient lacks capacity and a particular set of circumstances identified in the advance directive are deemed to apply. How this may work if it were to be applied to assisted suicide is not entirely clear, and yet the argument has recently been made that it should.<sup>129</sup> And yet, it seems that by arranging for this to happen the opportunity for abuse would increase significantly, as doctors would not necessarily be present for an assisted suicide as they are for euthanasia. A demented patient would likely have no understanding of the purpose for the lethal prescription with which they would be provided. Who would then assist them? For supporters of advanced directives for assisted suicide, the very condition of dementia would seem to frustrate the intention, eventually leading to pressure to permit euthanasia instead.

Advance directives, even for circumstances not pertaining to PAD, are controversial, mainly because someone's interests, perspectives, and wishes may change significantly from the time the directive was written to when it is activated, but also because such directives can be broad and difficult to decipher with respect to specific circumstances that may arise.

Difficulties in writing an informed AED for application in case of dementia stem not only from unpredictable variation in dementia's stages and effects. Members of the disability community have forcefully addressed a related problem: people often think prospectively that they would find a particular disabling condition "unbearable" or "worse than death," only to find when they actually experience it that it is not nearly as bad as they thought it would be.<sup>130</sup>

The deeper and more general objection to Ads [advance directives] is that the very condition that effectuates them, the inability to participate in medical decision-making, often so dramatically changes the person's interests as to undercut the authority of the directive.<sup>131</sup>

Regardless of the above, euthanasia of patients with dementia has been occurring in The Netherlands and Belgium, but the data is very mixed.

In The Netherlands in 2000 and 2001, in a study of 114 dementia patients who had an AED, there were 5 cases where drugs were administered intentionally to end life.<sup>132</sup> The authors extrapolated the sample of 114 to the total number of cases in The Netherlands, concluding that there were "approximately 2200 demented patients with an advance euthanasia directive", but that "it was impossible to make a reliable estimate of the number of times that euthanasia was performed".<sup>133</sup> However, a rough estimate can be provided. If the extrapolation from the sample of 114 to yield a total of 2200 patients is used as a guide, then the 5 dementia patients in the sample who were euthanased would extrapolate to about 96 patients for The Netherlands each year. It is not clear from this study what stage of dementia the 5 patients who were euthanased experienced, but it is likely to have been advanced given that for most of the 114 cases, the conditions identified in the directive were deemed to apply.

More recently several authors have suggested that when dementia patients have been euthanased in Holland, all have been in the early stages and competent, or were considered competent by

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<sup>128</sup> Menzel PT & Steinbock B (2013) *Op. Cit.*

<sup>129</sup> *Ibid.*

<sup>130</sup> *Ibid.*

<sup>131</sup> *Ibid.*

<sup>132</sup> Rurup ML *et al.* (2005) Physicians' Experiences with Demented Patients with Advance Euthanasia Directives in the Netherlands. *J Am Geriatr Soc* 53:1138–1144.

<sup>133</sup> *Ibid.*

themselves and others at the time of euthanasia.<sup>134,135,136</sup> For example, de Boer *et al.* concluded, based upon 2007/2008 data, that “Advance directives for euthanasia are never adhered to in The Netherlands in the case of people with advanced dementia.”<sup>137</sup> Their research suggests there is an almost complete reluctance to adhere to an AED for dementia.<sup>138,139</sup> So even though the number of reported cases of euthanasia in patients with dementia has steadily increased from 12 in 2009 to 81 in 2014<sup>140</sup>, then 169 in 2017<sup>141</sup>, almost all involved patients deemed competent. There was just one case from 2012 where dementia was advanced, and therefore there could have been no consent.<sup>142</sup> The conclusion of these authors seems to be at odds with the research from 2000/2001 cited above. Also at odds with the 2007/2008 work is recent research from 2015, which shows that around 1.3% of Dutch physicians have complied with an AED for patients with *advanced dementia* - but how this may translate to cases per year is unknown.<sup>143</sup> Therefore, contrary to the claims of de Boer and others, euthanasia of patients with advanced dementia is happening in Holland, and such cases are controversial on the grounds of the failure of contemporaneous consent.

In Belgium, while there has been a steadily growing incidence in reported cases of euthanasia of patients with dementia – from a total of 5 for 2002-2007 to 14 in 2013 – these have been cases of early stage dementia where it was argued that the patient was sufficiently competent to choose death.<sup>144</sup> However, Cohen-Almagor cites at least one case that came before the Belgian courts in which the patient was “not fully lucid and had not given written consent”.<sup>145</sup>

Given the narrow definition of euthanasia in Holland and Belgium, wherein only those cases with an explicit request (at the time of euthanasia or by advance directive) count as euthanasia, is it possible that some of the cases of ‘the use of life ending drugs without an explicit request from the patient’ (that is, NVAE cases), could involve dementia patients? The answer is yes. In 2010 in Belgium, Chambaere *et al.* found that 21.1% of cases without an explicit request indeed involved dementia patients, and these patients were either incompetent or may have had compromised competency, as implied by there being no explicit request.<sup>146</sup> Moreover, there was no AED. Using the Belgian data from 2007 within the category of ‘ending of life without patient’s explicit request’, where there were 988 deaths<sup>147</sup>, and the 21.1% figure from Chambaere *et al.*, somewhere in the vicinity of 200 deaths each year in Belgium were of dementia patients who provided no consent at the time of euthanasia or via an AED.

The conclusion to be drawn from both the Dutch and Belgian data is that claims that dementia patients who are incompetent are not receiving euthanasia are incorrect. The difficulty is that getting to the facts is clouded by the particular use of terminology and categories. Intentionally ending life by using drugs without request is still euthanasia, even if not defined as such in the Dutch and Belgian surveys. While there appears to be no study from The Netherlands that identifies dementia patients

<sup>134</sup> de Boer ME *et al.* (2010) Advance directives for euthanasia in dementia: Do law-based opportunities lead to more euthanasia? *Health Policy* 98:256–262.

<sup>135</sup> de Boer ME *et al.* (2011) Advance Directives for Euthanasia in Dementia: How Do They Affect Resident Care in Dutch Nursing Homes? Experiences of Physicians and Relatives. *J Am Geriatr Soc* 59:989–996.

<sup>136</sup> de Beaufort ID & van de Vathorst S (2016) Dementia and assisted suicide and euthanasia. *J Neurol* 263:1463–1467.

<sup>137</sup> de Boer ME *et al.* 2011 *Op. Cit.*

<sup>138</sup> de Boer ME *et al.* 2010 *Op. Cit.*

<sup>139</sup> de Boer ME *et al.* 2011 *Op. Cit.*

<sup>140</sup> de Beaufort ID & van de Vathorst S (2016) *Op. Cit.*

<sup>141</sup> 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.

<sup>142</sup> *Ibid.*

<sup>143</sup> Bolt EE *et al.* (2015) Can physicians conceive of performing euthanasia in case of psychiatric disease, dementia or being tired of living? *J Med Ethics* 41(8):592-598.

<sup>144</sup> Dierickx S *et al.* (2017) Euthanasia for people with psychiatric disorders or dementia in Belgium: analysis of officially reported cases. *BMC Psychiatry* 17:203.

<sup>145</sup> Cohen-Almagor R (2016) First Do No Harm: Euthanasia of Patients with Dementia in Belgium. *J Medicine & Philosophy* 41:74-89.

<sup>146</sup> Chambaere K *et al.* (2010a) *Op. Cit.*

<sup>147</sup> Bilsen J *et al.* (2009) *Op. Cit.*



from amongst those euthanased without explicit request, it is likely that the situation is similar to that in Belgium, and hence that significant numbers of Dutch dementia patients who have not consented, either at the time of euthanasia or via an AED, have had their lives ended.

Even if it is not common for physicians to act upon AEDs for patients with advanced dementia, when asked whether they could conceive of doing so, in Holland between 29% and 44% answer in the affirmative, the percentage being lower amongst those who more frequently care for such patients.<sup>148,149</sup> Recent Belgian research suggests that the percentage is similar amongst dementia specialists.<sup>150</sup>

In Canada the experience with legal euthanasia is much briefer than in Holland or Belgium, and yet even higher numbers of physicians would be prepared to euthanase patients with advanced dementia.<sup>151</sup> If there was a written request and dementia was advanced, 45% of physicians support providing euthanasia. Notably, 14% would still do so *without* a written request. When dementia was terminal, these figures rise to 71% and 43% respectively. It is sobering that 43% of Canadian physicians would be prepared to provide *non-voluntary* active euthanasia for such dementia patients. If that many physicians are prepared to terminate the lives of vulnerable patients without their request, a practice even ardent supporters of euthanasia are often reluctant to accept, this may be an insight into the future for *all* vulnerable Canadians at the end of their life if they happen to lose competency for whatever reason. For caregivers who have much closer contact with patients the figures are even higher. For advanced dementia, 50% support euthanasia without any written request, rising to 72% for terminal dementia patients.<sup>152</sup>

For the remaining category of euthanasia, namely euthanasia by omission, there is even less evidence available. In 2013 in Belgium, in the first study of its kind that assessed CDS in dementia patients (many cases of which almost certainly involved the intention to end life, especially when combined with the denial of CANH), 11 of 117 (9.4%) patients in the study group with dementia received CDS.<sup>153</sup> Nine of the 11 had advanced dementia, only 2 received CANH, and only 4 had expressed wishes with regard to end of life care. Two of the patients were not terminal. Notably, for 3 of the patients, death was a struggle with problematic symptoms, and sedation was not effective. This is an issue that others have addressed. In their consideration of the voluntary refusal of food and fluids (VRFF) with CDS to end life, Rady and Verheijde express concern that,

CDS may blunt the wakefulness component of human consciousness without eradicating inner affective awareness of thirst and hunger. Owing to the absence of empirical evidence on the efficacy of CDS in managing distress, it may be argued that VRFF with sedation represents a cruel and inhumane method of terminating life.<sup>154</sup>

Globally, the incidence of dementia is rising, from approximately 50 million in 2018, to a projected 152 million by 2050.<sup>155</sup> The debate about whether euthanasia should be a part of the treatment for this condition is therefore a critical question, not only because of the huge numbers involved, but also because the nature of the condition challenges the view that euthanasia should only be for those who request it – dementia, at least in the later stages, is the paradigmatic example of a condition where someone cannot choose. Even in the earlier stages, compromised capacity and fear, perhaps

<sup>148</sup> Bolt EE *et al.* (2015) *Op. Cit.*

<sup>149</sup> Rurup ML *et al.* (2005) *Op. Cit.*

<sup>150</sup> Picard G *et al.* (2019) Dementia, End of Life, and Euthanasia: A Survey Amongst Dementia Specialists Organised by the Belgian Dementia Council. *J Alzheimers Dis* 69(4):989-1001.

<sup>151</sup> Bravo G *et al.* (2018) Quebec physicians' perspectives on medical aid in dying for incompetent patients with dementia. *Canadian J Public Health* 109:729–739.

<sup>152</sup> Bravo G *et al.* (2019) *Op. Cit.*

<sup>153</sup> Anquinet L *et al.* (2013) Continuous Deep Sedation Until Death in Nursing Home Residents with Dementia: A Case Series. *J Am Geriatr Soc* 61:1768–1776.

<sup>154</sup> Rady MY & Verheijde JL (2012) Distress from voluntary refusal of food and fluids to hasten death: what is the role of continuous deep sedation? *J Medical Ethics* 38(8):510-512.

<sup>155</sup> World Health Organisation (2019) Dementia. See <https://www.who.int/news-room/fact-sheets/detail/dementia> Accessed 20 March 2020.

unjustifiable fear, of what is to come, militate against presentation of euthanasia as an entirely free choice of the person concerned.

### *Psychiatric Patients*

The patient indicated that she had had a life without love and therefore had no right to exist (case 2012-46).<sup>156</sup>

The patient was an utterly lonely man whose life had been a failure (case 2013-21).<sup>157</sup>

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].<sup>158</sup>

These three cases of psychiatric euthanasia came from the summaries produced by the Dutch regional euthanasia review committees from 2011 to 2015, and provide some insight into the characteristics of those patients seeking euthanasia to end their lives. For anyone who has struggled with social isolation, depression, existential despair, and a sense of failure, experiences not uncommon to many, these sad words may resonate.

It is nearly two decades since prominent Australian euthanasia activist Philip Nitschke famously argued for a ‘peaceful pill’ for “the depressed, the elderly bereaved, the troubled teen.”<sup>159</sup> Such broad access for the emotionally disturbed and mentally ill has not happened, but in the intervening years, argument for psychiatric euthanasia has become more and more prominent, at the same time as its practice in The Netherlands and Belgium has steadily increased.

Expansion of access to euthanasia for psychiatric patients is an example of mission creep, a slippery slope by category expansion. In the frontline of convincing the public and politicians to legalise euthanasia, the topic is studiously avoided by advocates, only appearing on the radar once the initial ‘breakthrough’ happens.

Canada is a case in point. Euthanasia was made legal in 2016, where Medical Assistance in Dying (MAiD) was allowed only when ‘natural death’ was ‘reasonably foreseeable’. But at the earliest stages, the seeds of future expansion were laid as legislators inserted a requirement for a later independent review to consider MAiD for mature minors, in cases of advance requests, and for the mentally ill. Following the independent review report, in which “there remained five large areas of disagreement on fundamental key issues”<sup>160</sup>, eight of the members (*The Halifax Group*) wrote a separate report in favour of MAiD for psychiatric patients.<sup>161</sup> In response to that report, a different group of members of the independent review committee and external experts (*The Expert Advisory Group on Medical Assistance in Dying*) published an opposing reply, concerned that if the changes proposed by *The Halifax Group* were adopted in law, “Canada will become the most permissive jurisdiction in the world

<sup>156</sup> Dutch recipient of euthanasia or assisted suicide. Cited by 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.

<sup>157</sup> *Ibid.*

<sup>158</sup> 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.

<sup>159</sup> Lopez KJ (2001) Euthanasia sets sail. An interview with Philip Nitschke, the other “Dr. Death.” *National Review*. See <https://www.nationalreview.com/2001/06/euthanasia-sets-sail-kathryn-jean-lopez/> Accessed 21 Feb 2020

<sup>160</sup> Expert Advisory Group on MAiD (2020) Canada at a Crossroads: Recommendations on Medical Assistance in Dying and Persons with a Mental Disorder - An Evidence-Based Critique of the Halifax Group IRPP Report. Toronto (ON):EAG. Doi: 10.13140/RG.2.2.36236.87687, p8. See

<https://static1.squarespace.com/static/5e3dcbaafb4d851392a9298f/t/5e4843a7dd83d25c7dc9140c/1581794218609/EAG+-+Canada+at+Crossroads+-+FINALdoi.pdf> Accessed 23 February 2020

<sup>161</sup> The Halifax Group (2020) MAiD Legislation at a Crossroads: Persons with Mental Disorders as Their Sole Underlying Medical Condition. IRPP Report (January). Montreal: *Institute for Research on Public Policy*. See <https://irpp.org/research-studies/maid-legislation-at-a-crossroads-persons-with-mental-disorders-as-their-sole-underlying-medical-condition/> Accessed 23 February 2020.

for MAiD.”<sup>162</sup> Clearly, psychiatric euthanasia in Canada is very much a hot topic. In the US, even though assisted suicide, but not euthanasia, is legal in nine states and the District of Columbia, but only for terminal illness, “attempts to extend physician-assisted death to psychiatric patients appear inevitable”.<sup>163</sup>

What are the main arguments in favour of and against expanding euthanasia and assisted suicide to include psychiatric patients, and how might they relate to informed consent?

The October 2019 issue of the *American Journal of Bioethics* dedicated significant space to the question of physician aid-in-dying (PAD) for psychiatric patients. In the target article (in response to which there were 13 open peer commentaries), the authors argued that PAD should be extended to psychiatric patients primarily because their suffering can be just as severe as physical suffering – this has been called the ‘parity argument’.<sup>164</sup> In this sense, to deny PAD to psychiatric patients would be discriminatory.

But an argument based upon discrimination alone is thin<sup>165,166,167,168</sup>, and does not take into account a variety of other important considerations that must be evaluated as part of a comprehensive analysis of euthanasia and/or assisted suicide for mental health reasons.

First, in the context of mental illness, it is not possible for doctors to accurately determine medical futility; that is, to decide that a given psychiatric condition is irremediable, and that there is therefore no prospect of recovery or therapeutic improvement of any kind.

... it is essentially impossible to describe any psychiatric illness as incurable.<sup>169</sup>

... while the experience of suffering may be widespread and near universal, so too is the experience of change - and difference and the possibility of suffering looking different another day - as long as there is another day ...<sup>170</sup>

Mental illnesses are often episodic, multifactorial, and responsive to treatment, and new treatments are continually being developed, and progress made in understanding the major characteristics and determinants of mental illnesses. Importantly, mental illnesses can be sensitive to the physical and social environment. The social aspects of psychiatric disorders can be a major source of suffering, and most of these, whilst complex, are open to remedies of various sorts. Resorting to psychiatric euthanasia is an indictment upon the community and its failure to properly address well-known social risk factors for mental illness, and enabling psychiatric euthanasia weakens attempts to deal with those factors.

The argument for PAD for mental illness seems less a matter of a morally comparable response to suffering and more a substitute for an inadequate health care system, failures in biomedical research, and deficiencies in psychiatric diagnoses and treatments. The more fundamental moral and professional responsibility should be devoted to addressing structural failures that in themselves are forms of systemic oppression and coercion and sources of suffering.<sup>171</sup>

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<sup>162</sup> Expert Advisory Group on MAiD (2020) *Op. Cit.* p5

<sup>163</sup> Miller FG & Applebaum PS (2018) Physician-Assisted Death for Psychiatric Patients - Misguided Public Policy. *New Engl J Med* 378(10):883-885.

<sup>164</sup> Kious BM & Battin M (2019) Physician Aid-in-Dying and Suicide Prevention in Psychiatry: A Moral Crisis? *Am J Bioethics* 19(10):29-39.

<sup>165</sup> Nicolini ME *et al.* (2019) *Op. Cit.*

<sup>166</sup> van de Vathorst S (2019) Concerning the Basic Idea that the Wish to End Suffering Legitimizes Physician Aid in Dying for Psychiatric Patients. *Am J Bioethics* 19(10):1-2.

<sup>167</sup> Campbell CS (2019) The Unbearable Burden of Suffering: Moral Crisis or Structural Failure? *Am J Bioethics* 19(10):46-47.

<sup>168</sup> Bartlett VL & Finder SG (2019) “When the Fall Is All There Is...”: Refocusing on the Critical (Unique?) Characteristic of “Dying” in Physician Aid-in-Dying. *Am J Bioethics* 19(10):43-46.

<sup>169</sup> Kelly BD & McLoughlin DM (2002) Euthanasia, assisted suicide and psychiatry: a Pandora’s box. *Brit J Psychiatry* 181:278-279.

<sup>170</sup> Bartlett VL & Finder SG (2019) *Op. Cit.*

<sup>171</sup> Campbell CS (2019) *Op. Cit.*

Moreover, in agreeing to euthanasia for a patient, doctors - as powerful cultural figures - may end up reinforcing what the *illness* is 'telling' the patient.

... a clinician's willingness to comply with a request for physician-assisted death is counter therapeutic, since it involves an implicit endorsement of the patient's perspective that his or her life is worthless and there is no hope for improvement.<sup>172</sup>

In her account of the euthanasia death of Belgian woman Godelieva De Troyer, Rachel Aviv describes a woman who had struggled with depression her whole life and was estranged from her children and grandchildren. She was physically well, yet was euthanased, her distraught son only finding out afterwards. What haunts him is that he believed a "reunion with her children and grandchildren ... might have alleviated the loneliness that was at the core of her suffering".<sup>173</sup> He was angry with Distelmans, Godelieva's euthanasia doctor:

You went along with the madness of my mother! You went along with her tunnel vision, her defeatism. You've just taken away the suffering of one person and transposed it to another.<sup>174</sup>

Godelieva "had struggled to find three doctors who would say that she had an incurable illness, as the law required".<sup>175</sup> At least two psychiatrists thought her desire for death was misplaced, one concluding "she could still be helped."<sup>176</sup> This observation accords with research that shows a quarter of Dutch consultants in psychiatric euthanasia cases disagreed with one another about medical futility.<sup>177</sup>

The question of medical futility is central to informed consent. When a patient is reinforced in the belief that his or her situation is hopeless and that there are no alternative treatments available, that information influences consent. If the information is incorrect, or even debatable, then informed consent has failed. It seems inconceivable, as Vandenberghe points out, that the process of patient evaluation, with careful attention to all past and putative future treatment options, is less rigorous for psychiatric euthanasia than for a potentially therapeutic procedure like deep brain stimulation.<sup>178</sup>

Second, and of particular importance regarding the purpose of this paper, a psychiatric condition may compromise capacity, or eliminate it altogether. When someone's mental illness is severe enough for them to seek death, it is also likely to be severe enough to interfere with their capacity to make a voluntary choice. In a study of Dutch psychiatrists conducted shortly after the 1994 Dutch Supreme Court ruling that permitted psychiatric euthanasia in exceptional circumstances, of the 320 requests by patients per year, in only 32% were the patients deemed competent.<sup>179</sup> And yet for those perhaps closest to their patients, psychiatric nurses, the majority (86%) agreed with euthanasia for mental illness at the same time as more than half (54%) were uncertain about decision-making capacity or thought it was absent.<sup>180</sup>

Judgement about capacity is not a simple task. A patient needs " ... to understand relevant facts, apply those facts to oneself, reason and weigh the facts, and evidence a stable choice."<sup>181</sup> However, in their study of the available Dutch psychiatric euthanasia cases up till June 2015, Doernberg *et al.* found that in only 8% of cases was there any mention of all four abilities. The authors refer to several of the

<sup>172</sup> Miller FG & Applebaum PS (2018) *Op. Cit.*

<sup>173</sup> Aviv R (2015) The Death Treatment: When should people with a non-terminal illness be helped to die? *The New Yorker* See <https://www.newyorker.com/magazine/2015/06/22/the-death-treatment> Accessed 20 Jun 2019.

<sup>174</sup> *Ibid.*

<sup>175</sup> *Ibid.*

<sup>176</sup> *Ibid.*

<sup>177</sup> Kim SYH *et al.* (2016) *Op. Cit.*

<sup>178</sup> Vandenberghe J (2018) Physician-Assisted Suicide and Psychiatric Illness. *New Engl J Med* 378(10):885-887.

<sup>179</sup> Groenewoud JH *et al.* (1997) Physician-Assisted Death in Psychiatric Practice in The Netherlands. *New Engl J Med* 336(25):1795-801.

<sup>180</sup> De Hert M *et al.* (2015) Attitudes of Psychiatric Nurses about the Request for Euthanasia on the Basis of Unbearable Mental Suffering (UMS). *PLoS ONE* 10(12): e0144749. doi:10.1371/journal.pone.0144749

<sup>181</sup> Doernberg SN *et al.* (2016) Capacity Evaluations of Psychiatric Patients Requesting Assisted Death in the Netherlands. *Psychosomatics* 57:556-565.

patient case notes about capacity determinations in which there was significant disagreement amongst physicians, specialists and psychiatrists. In over half of cases “only global judgements of patients’ capacity, even in patients with psychotic disorders” were made.<sup>182</sup> Moreover, the Dutch euthanasia review committees, rather than maintaining a high standard for capacity determinations, seem to operate from a low threshold position, as evidenced by their acceptance that all but one of 85 cases of psychiatric euthanasia had met the due care criteria.<sup>183</sup>

Third, the community at large, and the profession of psychiatry in particular, have always been committed to suicide prevention, to helping someone with suicidal thoughts to avoid the distortions of thinking that accompany such ideation, and to revive the will to live and recover, or at the very least, receive palliation. Participating in psychiatric euthanasia places psychiatrists in a fraught position and may change the profession forever.

... the concept of assisting – rather than preventing – suicide counters the core aims of psychiatric practice. The shift of therapeutic role from alleviating psychic despair to facilitating suicide would be anathema to many psychiatrists.<sup>184</sup>

What prompted the discussion in the *American Journal of Bioethics* referred to above was a paper that considered the juxtaposition of suicide prevention, in the extreme form of involuntary institutional commitment, with the expanding desire for including psychiatric euthanasia in the repertoire of medical assistance to die.<sup>185</sup> How is it possible on the one hand to protect people from themselves by having them committed involuntarily, and yet on the other to enable their deaths under what are essentially the same conditions? And they *are* essentially the same<sup>186</sup>, despite a prominent denial from the *American Association of Suicidology*.<sup>187</sup>

While this particular issue may seem only indirectly related to the business of consent to euthanasia or assisted suicide, failure of a unified commitment against suicide risks a contagion effect, itself surely evidence of influence over vulnerable individuals in their free choices. This will be explored further in the next section.

Current knowledge about the actual practice of psychiatric euthanasia is limited. Studies are few and far between precisely at the time they are needed most, as serious debate is happening, and countries like Canada seem on the verge of endorsing psychiatric euthanasia.

In The Netherlands the official numbers of reported cases are small but increased from 0 in 2008 to 83 in 2017.<sup>188</sup> Despite these figures, as early as 1997 it was estimated that there were between 2 and 5 cases per year<sup>189</sup>, which may constitute evidence of poor reporting as occurs in other categories of euthanasia. For a one-year period from 2015 to 2016, there were estimated to be between 1100 and 1150 explicit requests for psychiatric euthanasia<sup>190</sup>, a figure that has more than trebled since 1997.<sup>191</sup> The majority of those who were euthanased (2011 to 2014) were women (70%), and the types of cases included depressive disorders, personality disorders, psychosis, posttraumatic stress or anxiety,

<sup>182</sup> *Ibid.*

<sup>183</sup> *Ibid.*

<sup>184</sup> Kelly BD & McLoughlin DM (2002) *Op. Cit.*

<sup>185</sup> Kious BM & Battin M (2019) *Op. Cit.*

<sup>186</sup> Kim SYH *et al.* (2018) *Op. Cit.*

<sup>187</sup> “The American Association of Suicidology recognizes that the practice of physician aid in dying, also called physician assisted suicide, Death with Dignity, and medical aid in dying, is distinct from the behavior that has been traditionally and ordinarily described as “suicide,” the tragic event our organization works so hard to prevent. Although there may be overlap between the two categories, legal physician assisted deaths should not be considered to be cases of suicide and are therefore a matter outside the central focus of the AAS.” *American Association of Suicidology* (2017) Statement of the American Association of Suicidology: “Suicide” is not the same as “Physician Aid in Dying”. p1 See <https://suicidology.org/wp-content/uploads/2019/07/AAS-PAD-Statement-Approved-10.30.17-ed-10-30-17.pdf> Accessed 20 February 2020. For a commentary and critique see Kim SYH *et al.* (2018) *Op. Cit.*

<sup>188</sup> 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.

<sup>189</sup> Groenewoud JH *et al.* (1997) *Op. Cit.*

<sup>190</sup> Evenblij K *et al.* (2019) *Op. Cit.*

<sup>191</sup> Groenewoud JH *et al.* (1997) *Op. Cit.*

eating disorders, substance abuse, prolonged grief, and autism.<sup>192</sup> Rather than acting only as consultants, psychiatrists enacted euthanasia in over 40% of cases<sup>193</sup>, and one third of all Dutch psychiatrists could conceive of performing psychiatric euthanasia.<sup>194</sup> The End-of-Life Clinic, a mobile clinic “affiliated with the largest Dutch euthanasia advocacy organisation”<sup>195</sup>, has become increasingly involved in psychiatric euthanasia cases, reporting 62% of the total for 2017.<sup>196</sup>

The evidence from Belgium is similar. Whereas there was approximately one reported case of psychiatric euthanasia per year from 2002 to 2007, numbers rose steadily to 60 in 2015 before dropping to about 40 per year in 2016 and 2017.<sup>197,198</sup> Again, women were over-represented (77%), and the conditions patients suffered from were similar. However, in a separate study of 100 Belgian psychiatric patients seeking euthanasia, the types of conditions were more narrowly focused - 19 had a diagnosis of Asperger Syndrome.<sup>199</sup> Since the 100 patients for this study sought out one particular clinic, it is not clear how representative this sample was of all requests for psychiatric euthanasia in Belgium. This group was also particularly young – 22 were aged between 20 and 40, and 46 between 40 and 60.<sup>200</sup> 48 of the 100 were approved for euthanasia and 35 received it. In a separate study of 26 of the 100 patients, the majority of whom were granted their euthanasia request, the nature of their unbearable suffering was explored. Patients identified five domains: medically related suffering, intrapersonal suffering, suffering related to interpersonal interaction, suffering related to one’s place and interaction in society, and existential suffering. What the study revealed was that a significant burden of suffering resulted from serious disruptions to important relationships, social isolation and loss, poor socioeconomic circumstances, agonizing over questions of meaning, and the perception of patients that they were a burden on society.<sup>201</sup>

To summarise this section, psychiatric euthanasia is at the leading edge of euthanasia debate<sup>202</sup>, and while the numbers are currently small in The Netherlands and Belgium, they have grown steadily over time. The evidence is limited, but it is known that the majority of cases involve women and that a broad spectrum of illness types are represented. Because knowledge about mental illnesses and their treatment is inadequate, it is impossible to say that any particular case is irremediable. This vulnerable patient group is at particular risk of compromised capacity, about which there is significant difference of opinion amongst the practitioners to whom these patients go for help.

## Coercion, Pressure, and Culture

Someone contemplating the profound decision to end their life may look to a variety of sources for relevant information, some professional and some not. They will also in all likelihood reflect internally upon their own values and experience, and externally look to the opinions and considered judgements of loved ones, professionals, and others. They may consider costs and benefits, perceived short and long term outcomes for those close to them, and social norms and expectations of their subcultural grouping, as well as the wider culture within which they live. This may sound idealistic - because it is.

<sup>192</sup> Kim SYH *et al.* (2016) *Op. Cit.*

<sup>193</sup> *Ibid.*

<sup>194</sup> Bolt EE *et al.* (2015) *Op. Cit.*

<sup>195</sup> Kim SYH (2019) How Dutch Law Got a Little Too Comfortable With Euthanasia. The story of a 17-year-old’s assisted death wasn’t real - but it could have been.

See <https://www.theatlantic.com/ideas/archive/2019/06/noa-pothoven-and-dutch-euthanasia-system/591262/> Accessed 27 February 2020.

<sup>196</sup> Evenblij K *et al.* (2019) *Op. Cit.*

<sup>197</sup> Dierickx S *et al.* (2017) *Op. Cit.*

<sup>198</sup> Verhofstadt M *et al.* (2019) Psychiatric patients requesting euthanasia: Guidelines for sound clinical and ethical decision making. *Int J Law & Psychiatry* 64:150–161.

<sup>199</sup> Thienpont L *et al.* (2015) Euthanasia requests, procedures and outcomes for 100 Belgian patients suffering from psychiatric disorders: a retrospective, descriptive study. *BMJ Open* 5:e007454. doi:10.1136/bmjopen-2014-007454.

<sup>200</sup> *Ibid.*

<sup>201</sup> Verhofstadt M *et al.* (2017) When unbearable suffering incites psychiatric patients to request euthanasia: qualitative study. *Brit J Psychiatry* 211:238-245.

<sup>202</sup> Verhofstadt M *et al.* (2019) *Op. Cit.*

In reality, such multifaceted deliberations by someone who is distressed and suffering will be incomplete at best and potentially skewed - because of their circumstances (eg social isolation) and the nature of their suffering. But more importantly, because they will be subject to a variety of influences. Those influences can be overt, or they can be subtle, yet in either case they may be potent. They can amount to serious pressure and coercion that compromises a free choice.

But why should the question of influence concerning decisions about euthanasia and assisted suicide be subject to particular scrutiny? After all, decision-making *in general* is subject to influence. In fact, it is common for professionals, loved ones, and others to try to influence someone's healthcare decisions for the better, to encourage a decision that is judged to be in their best interests. Generally this is applauded. But there at least three reasons why, when it comes to legal euthanasia and assisted suicide, the question of choice is so important – and acknowledged to be so, given the attempts to provide safeguards to try and ensure that choices are well-considered, persistent, and freely made.

First, people who contemplate euthanasia or assisted suicide are often, if not always, vulnerable in some way. In fact, it could be argued that anyone prepared to countenance the thought of ending his or her life is *inherently* vulnerable. After all, suffering creates vulnerability, and vulnerable people are at risk in ways the healthy and well are not. Battin *et al.* claim that there is no evidence from Oregon or The Netherlands that legal physician-assisted dying disproportionately impacts vulnerable individuals<sup>203</sup>, a view rejected by Finlay and George<sup>204</sup>, who argue that the methodology used by Battin *et al.* did not consider a range of categories of vulnerability at the same time as it assumed vulnerability on some grounds that were unjustifiable. Moreover, Finlay and George further contend that even for some of the categories chosen, the evidence does in fact show a disproportionate impact on vulnerable people.

Second, some family, friends, organisations, and the state, have an interest in enabling euthanasia. Many will find that a shocking statement, and recoil at the suggestion, instead arguing that euthanasia is simply about dealing with suffering and respecting autonomy. But the more base side of human nature needs to be faced squarely. Sometimes, the burden and cost of caring for the sick, aged, and disabled evokes a desire to be relieved of that burden and cost, and some will act upon that desire.

Finally, life is an inherent good, as the *Universal Declaration of Human Rights* states. Death is not. Coercion to live is fundamentally different to coercion to die. Life has hope and possibilities that death does not. The community invests in suicide prevention to help people see that no matter how bad it seems, life is worth continuing, and even at times enduring. Is that not pressure? And does not involuntary commitment for self-protection involve coercion, if not force, to avoid self-destruction? So the question is not whether influence, or even pressure and coercion are in themselves wrong, but rather, what is their motivation and goal.

In this section, sources of undue influence that place particular groups at risk of 'choosing' to end their lives will be explored. Without these influences, people might otherwise choose to live. Some may even feel that in the end they really had 'no choice' but to die.

### *Organ Donation*

Organ donation after euthanasia is still a relatively rare phenomenon; however, the numbers have been increasing in The Netherlands and Belgium, where since 2005 at least 70 people have donated their organs after euthanasia.<sup>205</sup> In Belgium, 9 patients donated organs after euthanasia from 2005 to 2012, a rate of approximately 1.3 per year, compared with 7 for 2012 and 2013, a rate of 3.5 per

<sup>203</sup> Battin MP *et al.* (2007) Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in "vulnerable" groups. *J Med Ethics* 33:591-597.

<sup>204</sup> Finlay IG & George R (2011) Legal physician-assisted suicide in Oregon and The Netherlands: evidence concerning the impact on patients in vulnerable groups - another perspective on Oregon's data. *J Med Ethics* 37:171-174.

<sup>205</sup> Bollen JAM *et al.* (2019) Euthanasia through living organ donation: Ethical, legal, and medical challenges. *J Heart Lung Transplant* 38:111-113.

year.<sup>206</sup> In Canada, the numbers have outstripped those in Belgium and The Netherlands combined over a much shorter time frame - from 2016 to January 2019, there were 30 donors who donated 74 organs<sup>207</sup>, but for the first 11 months of 2019, in Ontario alone, there were 18 donors, a figure up 14 percent on 2018 and 109 percent on 2017.<sup>208</sup>

Arguments for combining euthanasia and organ donation are primarily utilitarian<sup>209</sup>, some even suggesting that because it is economically sound, that should factor into the decision.<sup>210</sup>

There are two key reasons why, despite the experience in The Netherlands, Belgium and Canada, combining euthanasia with organ donation has been treated so cautiously, if not opposed outright. The first is that the process of organ donation may be modified because of this particular end-of-life context. While it has been widely agreed that organ donation can only occur after the patient is dead (the dead donor rule), an increasing number of ethicists and others have argued that allowing organ removal to be the *means* of death would have a range of desirable outcomes, and euthanasia remains the ideal setting for this because the patient actually wants to die.<sup>211,212,213,214</sup> However, were euthanasia to be so directly linked with retrieving organs, the public may perceive that people are being euthanased *for* their organs, potentially damaging the altruistic underpinnings of organ donation.<sup>215</sup>

The second matter, and the one that is most pertinent for the purposes of this review, is the risk that the benefit of organ donation to one or more other people may be a decisive factor in someone's choice for euthanasia. Choice may not be so free after all, but may instead be influenced by the thought that at least something good may come from death.

It has always been a parallel thought process for me. I thought the knowledge of having full autonomy by way of MAiD was comforting, but, when the possibility of organ donation was added to it, the sense of elation is the only appropriate word for me. It is so exciting to know that I have the potential to alleviate the suffering of someone on a wait list.<sup>216</sup>

Organ donation after euthanasia has been described by some as “a pure act of altruism fulfilling the patient's last wish”.<sup>217</sup> Alternatively, it may be seen as coercion that pushes a vulnerable person to decide upon death when they otherwise might not.<sup>218</sup>

The way this dilemma has been addressed, where euthanasia with organ donation is permitted, is to attempt a strict separation of the request for euthanasia from the decision to donate organs, an idea that is widely promoted as the solution to any concern about pressure.<sup>219,220</sup>

<sup>206</sup> van Wijngaarden AKS *et al.* (2016) Organ Donation After Euthanasia in the Netherlands: A Case Report. *Transplantation Proceedings* 48:3061-3063.

<sup>207</sup> Ball IM *et al.* (2020) Organ Donation after Medical Assistance in Dying - Canada's First Cases. *New Engl J Med* 382(6):576-577.

<sup>208</sup> Deachman B (2020) Medically assisted deaths prove a growing boon to organ donation in Ontario, Ottawa Citizen. See <https://ottawacitizen.com/news/local-news/medically-assisted-deaths-prove-a-growing-boon-to-organ-donation-in-ontario> Accessed 16 March 2020.

<sup>209</sup> Lazaridis C & Blumenthal-Barby JS (2015) Organ Donation Beyond Brain Death: Donors as Ends and Maximal Utility. *Am J Bioethics* 15(8):17-19.

<sup>210</sup> Shaw D & Morton A (2020) Counting the Cost of Denying Assisted Dying. *Clinical Ethics* (In Press).

<sup>211</sup> Shaw DM (2014) Organ Donation After Assisted Suicide: A Potential Solution to the Organ Scarcity Problem. *Transplantation* 98:247-251.

<sup>212</sup> Bollen JAM *et al.* (2019) *Op. Cit.*

<sup>213</sup> Lazaridis C & Blumenthal-Barby JS (2015) *Op. Cit.*

<sup>214</sup> Cronin AJ (2014) Death by Donation: Reflections on Individual Authorization, Assisted Suicide and Organ Donation. *Transplantation* 98(3):254-256.

<sup>215</sup> Bollen JAM *et al.* (2019) *Op. Cit.*

<sup>216</sup> *Ibid.*

<sup>217</sup> Bollen J *et al.* (2017) Organ Donation After Euthanasia: A Pure Act of Altruism Fulfilling the Patient's Last Wish. *Am J Transplantation* 20:1-2. The authors do not wish to deny patients the opportunity for altruism after euthanasia, which represents an “unfortunately unavoidable medical situation”.

<sup>218</sup> Chen E (2014) Organ Donation After Assisted Suicide: Practically and Ethically Challenging. *Transplantation* 98:252-253.



A patient contemplating medical assistance in dying (MAiD) must not be regarded as an organ donor but as a person wishing to do a good deed at the end of life.<sup>221</sup>

But this is misleading about what actually happens, and strict separation is unrealistic. With the existing high level of public knowledge about organ donation, coupled with increasing awareness of combining euthanasia and organ donation, as well as the multiplicity of conversations between the patient, doctors, support staff, as well as with family and friends, the possibility of organ donation is likely to already be on the patient's radar. Bollen *et al.* acknowledge the difficulty<sup>222</sup>, yet argue “... that a physician should always inform a patient who is medically suitable [for MAiD] about the possibility of organ donation, even if this could disrupt the trust relationship ...”.<sup>223</sup> The organisation responsible for ethics in science and technology in Quebec similarly wants healthcare institutions to ensure patients eligible for MAiD are informed about organ donation.<sup>224</sup> Shaw & Morton point out that “patients who choose assisted dying have to go through a lengthy process, and organ donation can be easily integrated into that process (non-coercively)”.<sup>225</sup> But the pressure already exists, and process alone cannot solve the problem.

The difficulty is how to ensure a doctor, or for that matter anyone else close to the patient, who is committed to the idea that organ donation after euthanasia is good, if not a moral requirement on utilitarian grounds, will not, in subtle or less subtle ways, influence a patient. Shaw and Morton sharpen the point:

Consider the case of a dying consequentialist. Her healthcare costs in her last agonising few months push the overall cost-benefit calculation for her life into the red: alongside the physical and psychological trauma of dying, she now must bear the moral horror of having consumed more than she has produced, and made a negative net contribution to the world. Hence, we see assisted dying as enabling patients to live lives which are more fully consistent with their own ethical values (consequentialist or not).<sup>226</sup>

Weighing the value of life in cost-benefit terms can have a disastrous effect on someone's sense of self. Views of elites who think some lives are of no value because they have made a ‘negative net contribution to the world’ are, quite simply, deadly. And this can apparently apply to non-consequentialists as well. This should be a red flag for how any patient may be affected by certain healthcare professionals who may think similarly. Moreover, with the rise of psychiatric euthanasia, patients whose very condition disposes them to think their lives have made a ‘negative net contribution to the world’ could be at great risk of ‘choosing’ euthanasia to donate their organs and redress the balance. Respecting such an ‘autonomous’ wish may have less to do with the good of the patient and more to do with helping someone else who is seen as more worthy.

### Prisoners

Serious offenders in prison represent a population who are unlikely to get much sympathy from the public. The case of Belgian Frank Van Den Bleeken has stimulated debate about whether euthanasia should be extended to prisoners, and while Van Den Bleeken's request for euthanasia was granted, it

<sup>219</sup> Ball IM *et al.* (2018) Voluntary Euthanasia — Implications for Organ Donation. *New Engl J Med* 379(10):909-911.

<sup>220</sup> Ysebaert D *et al.* (2009) Organ Procurement After Euthanasia: Belgian Experience. *Transplantation Proceedings* 41:585–586.

<sup>221</sup> Mulder J & Sonneveld JPC (2018) Organ donation after medical assistance in dying at home. *Canadian Med Assoc J* 190(44):E1305-E1306.

<sup>222</sup> Bollen JAM *et al.* (2019) *Op. Cit.*

<sup>223</sup> *Ibid.*

<sup>224</sup> Allard J & Fortin M-C (2017) Organ donation after medical assistance in dying or cessation of life-sustaining treatment requested by conscious patients: the Canadian context. *J Med Ethics* 43:601–605.

<sup>225</sup> Shaw D & Morton A (2020) *Op. Cit.*

<sup>226</sup> *Ibid.*

was never carried out.<sup>227</sup> In the meantime, many other Belgian prisoners have requested euthanasia.<sup>228</sup> In the rapidly progressing Canadian context, by the start of 2018 at least one prison inmate had been euthanased, and two others had received approval.<sup>229</sup>

Euthanasia for prisoners has received support, often on the basis of an argument from mercy.<sup>230,231,232,233</sup> However, in addition to that particular motive, but more worrying from the perspective of humane treatment, is the fact that many regard such people as the dregs of society who would be missed by virtually no one. In other words, if they wish to die, well and good. Moreover, the cost savings for the most serious cases, who are typically incarcerated for life, could be appealing. Porremeister *et al.* are open about this:

... the choice of PAS [Physician Assisted Suicide] as a means of mercy as an alternative to life in prison would eliminate costs of incarceration that accumulate during a prisoner's lifetime.<sup>234</sup>

Saving a substantial amount of money by euthanasing serious offenders, for whom there is little sympathy, is a volatile mix that would almost certainly coerce some prisoners to seek death. As it is, suicide is six times higher amongst inmates compared with the wider population, so the desire for death is evident.<sup>235</sup> Arguments based upon respecting autonomy in a system designed to restrict it do not hold the same meaning compared with other contexts. Belgium in particular has a harsh and inhumane prison system, especially with regard to disabilities and mental health:

Belgium has a deplorable reputation regarding the treatment of prisoners and detainees with intellectual disabilities or psychiatric disorders who are held in custody, as a preventative measure. The European Court of Human Rights has condemned Belgium several times for not providing adequate care for prisoners and detainees, even accusing it of falling short of its obligations under the United Nations Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment.<sup>236</sup>

With wider acceptance of euthanasia for psychiatric reasons, coupled with cost savings regarding people who are widely despised, there are ample reasons why the expansion of euthanasia to prisoners is appealing to some. Voluntary consent for people behind bars, let alone if they are also mentally ill, cannot apply in the same way as it might for the population at large.

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<sup>227</sup> Cook M (2017) What's wrong with prisoner euthanasia? A US law journal investigates "the last frontier in prison reform" *MercatorNet* See <https://www.mercatornet.com/careful/view/whats-wrong-with-prisoner-euthanasia/19923> Accessed 16 March 2020.

<sup>228</sup> Devolder K (2016) Euthanasia for Detainees in Belgium. The Case of Frank Van Den Bleeken. *Cambridge Quart Healthcare Ethics* 25:384-394.

<sup>229</sup> Harris K (2018) Watchdog calls for compassionate parole as prison system adopts new assisted death policy. *CBC News Canada* See <https://www.cbc.ca/news/politics/terminally-ill-inmates-csc-zinger-maid-1.4546773> Accessed 17 March 2020.

<sup>230</sup> Devolder K (2016) *Op. Cit.*

<sup>231</sup> Porremeister K *et al.* (2017) Physician Assisted Suicide as a Means of Mercy: A Comparative Analysis of the Possible Legal Implications in Europe and the United States. *Virginia J Social Policy & Law* 24:1-23.

<sup>232</sup> Brown C (2014) Some inmates should have the right to euthanasia. *New Scientist* See <https://www.newscientist.com/article/dn26233-some-inmates-should-have-the-right-to-euthanasia/> Accessed 19 March 2020.

<sup>233</sup> Nitschke P (2014) Euthanasia is a rational option for prisoners facing the torture of life in jail. *The Guardian (Australian Edition)* See <https://www.theguardian.com/commentisfree/2014/sep/27/euthanasia-is-a-rational-option-for-prisoners-facing-the-torture-of-life-in-jail> Accessed 17 March 2020.

<sup>234</sup> Porremeister K *et al.* (2017) *Op. Cit.* p18

<sup>235</sup> World Health Organisation (2014) Preventing Suicide in Jails and Prisons. *WHO Department of Mental Health and Substance Abuse*. See [https://www.who.int/mental\\_health/prevention/suicide/resource\\_jails\\_prisons.pdf](https://www.who.int/mental_health/prevention/suicide/resource_jails_prisons.pdf) Accessed 22 February 2020.

<sup>236</sup> Devolder K (2016) *Op. Cit.* p385

## Burden

... 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.<sup>237</sup>

Baroness Warnock made these comments<sup>238</sup> in relation to dementia sufferers, but being a burden, perceived on the part of the patient and/or real in the experience of those close to him or her, could equally apply to a wide range of health conditions, or by virtue of being old enough to require much more care than at any other time in life. As a key figure of authority, Baroness Warnock is not alone. Over twenty years ago, writing in *The Hastings Center Report*, Hardwig answered the question “Is there a duty to Die?” with an emphatic yes, implying that there is no inherent right to life.

Modern medicine and an individualistic culture have seduced many to feel that they have a right to health care and a right to live, despite the burdens and costs to our families and society.<sup>239</sup>

Hardwig was writing in 1997, the year that Oregon’s Death with Dignity Act was passed. He refers to the Act at the outset, the implication being that a duty to die might be put into effect by assisted suicide.

More recently, others have been more explicit and calculating about the burden placed on family, loved ones and the community by continued living.

... a patient who is in great pain because of cancer with a life expectancy of around two years will continue to require pain medication and support from clinical staff and also carers for those two years. For each such patient, legalising assisted dying would avoid this waste of resource.<sup>240</sup>

In the UK alone, Shaw and Morton argue, this ‘wasted resource’ could instead save up to seventy-four million pounds if assisted dying were allowed.<sup>241</sup> The authors are quick to add “ ... in no way is it intended to suggest that any such care should be denied to any patient”.<sup>242</sup> But that is precisely what the patient in such a condition will perceive *is* being implied by the argument that if they would choose death instead of ongoing care they will save money for ‘more worthy’ causes.

The argument that euthanasia and assisted suicide of people towards the end of life represents a cost saving for the community has particular force given the aging population in many countries and the increasing costs of care that are spent particularly upon this demographic. That euthanasia and assisted suicide may mean significant cost savings for the community at large is rarely heard in public debate. It has been decried by euthanasia advocates as being in bad taste.

I suggested to Pleiter [Director of the Dutch End-of-Life Clinic] that the insurance companies must prefer to pay a one-off fee for euthanising someone to spending a vast sum in order to keep that person, needy and unproductive, alive in a nursing home. Pleiter’s pained expression suggested that I had introduced a note of cynicism into a discussion that should be conducted on a more elevated plane. “There’s not an atom in

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<sup>237</sup> Warnock Baroness BM (2008) *Op. Cit.*

<sup>238</sup> The comment is particularly notable for its effortless slide from being ‘allowed to die’ to having a ‘duty to die’ by euthanasia. The two are quite different, and their conflation unfortunately obfuscates rather than clarifies.

<sup>239</sup> Hardwig J (1997) Is there a duty to die? *Hastings Center Report* 27(2):34-42.

<sup>240</sup> Shaw D & Morton A (2020) *Op. Cit.*

<sup>241</sup> *Ibid.*

<sup>242</sup> *Ibid.*

my body that is in sympathy with what you are describing,” he replied. “This isn’t about money ... it’s about empathy, ethics, compassion.”<sup>243</sup>

Whether most or even all euthanasia advocates think similarly is not the point. The reality is that the (unspoken) views of the insurers, medical directors, health economists, politicians and other financial decision makers are that ones that count. The cost of care that could be saved by euthanasia is an ‘elephant in the room’ that few may wish to speak about, but which may play a role by applying pressure to the aged, sick and frail to ‘choose’ euthanasia or assisted suicide to alleviate the cost to the community.

That someone in need of extensive care at the end of life might perceive themselves to be a burden does not need encouragement from authority figures. Patients in that position already feel they are a burden, and are aware that the financial and other costs associated with their care are higher than for others, often much higher. Nearly half of Americans would consider an alternative such as assisted death because they do not want to burden their families.<sup>244</sup> Moreover, 60% are worried about being a financial burden on their children or others as they age.<sup>245</sup> And approximately 40% of patients who died under the Oregon Death with Dignity Act had cited burden on family friends and caregivers as an end of life concern.<sup>246</sup> 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 problem.<sup>247</sup> Some studies identified in their review went further and specifically linked the perception of being a burden to a desire for hastened death.<sup>248,249</sup>

Patients also find endorsement of their fears in the views of those close to them. At a time when legal assisted suicide was on the threshold of implementation in the US (1996/1997), 29% of caregivers supported euthanasia or assisted suicide for “patients who believed they were a burden”.<sup>250</sup> The general public (31%-38%) as well as US physicians (21%-24%) also support assisted suicide if patients perceive they are a burden to others.<sup>251</sup>

But is it really necessary to remove burden by being relieved of the person at the centre of it? Instead, might it not be a characteristic of a just society to accept the reality of the costs of ill health and aging, and care for the sick, frail, and elderly because of the inherent value of all human lives, and help them to feel that this is warranted because of their intrinsic value? Perhaps characterising the work of care itself as burdensome is the problem. Instead such care could be seen as simply an intrinsic part of what humans do, maybe even a privilege.

Rather than thinking of aging persons as a net drain on society, or an unfortunate “burden” to be borne by families, we should instead view them – as we do the very young – as deserving of our care.<sup>252</sup>

<sup>243</sup> de Bellaigue C (2019) Death on demand: has euthanasia gone too far? *The Guardian* See <https://www.theguardian.com/news/2019/jan/18/death-on-demand-has-euthanasia-gone-too-far-netherlands-assisted-dying> Accessed 28 February 2020.

<sup>244</sup> Blendon RJ *et al.* (1992) Should Physicians Aid Their Patients in Dying? The Public Perspective. *JAMA* 267(19):2658-2662.

<sup>245</sup> Americans View Aging: Results of a National Survey Conducted for the Alliance for Aging Research. Washington, DC: Belden & Russonello Research and Communications; November 1991. Cited by Blendon RJ *et al.* (1992) *Op. Cit.*

<sup>246</sup> Oregon Public Health Division (2014) Oregon’s Death with Dignity Act - 2014. See <https://www.oregon.gov/oha/ph/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year17.pdf> Accessed 14 March 2020.

<sup>247</sup> 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.

<sup>248</sup> Ganzini L *et al.* (2002) Predictors and Correlates of Interest in Assisted Suicide in the Final Month of Life Among ALS Patients in Oregon and Washington. *J Pain Sympt Management* 24(3):312-317.

<sup>249</sup> 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.

<sup>250</sup> Emanuel EJ *et al.* (2000) Attitudes and Desires Related to Euthanasia and Physician-Assisted Suicide Among Terminally Ill Patients and Their Caregivers. *JAMA* 284(19):2460-2468.

<sup>251</sup> McPherson CJ *et al.* (2007) *Op. Cit.*

<sup>252</sup> Jecker NS (2014) Against a Duty to Die. *Am Med Soc J Ethics* 16(5):390-394.

... 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.<sup>253</sup>

Concern that the frail and elderly may feel pressured to accept euthanasia or assisted suicide is sharpened by the prevalence of elder abuse. Elder abuse can take many forms, including physical, psychological and emotional, sexual, financial abuse and neglect; and the prevalence appears to be around the 10% mark, although there are reasonable grounds to consider this an underestimate.<sup>254</sup> The incidence may also be rising<sup>255</sup>, and most abuse comes from spouses and adult children.<sup>256</sup>

When the frail elderly are being subjected to abuse by those closest to them, it would be unsurprising if the resultant misery would not drive some towards considering a legally sanctioned assisted death. Moreover, in many families there is an incentive to encourage an earlier than natural death specifically for financial gain, namely to more quickly gain access to an inheritance.

Financial exploitation of older adults ... has recently been identified as a virtual epidemic ...<sup>257</sup>

If family members and other carers are prepared to financially abuse an older person in their care, why would they also not encourage their departure sooner if there is an inheritance waiting? This is a nasty characteristic of the way some people will behave, but legal access to euthanasia or assisted suicide provides an incentive for some to apply pressure for a rapid exit. And that pressure need not be overt.

In these matters, families cannot be neutral. Even if they say, "It's up to you Mom," when asked their opinion about a proposed suicide, their reply is correctly heard as indifference about the life in question.<sup>258</sup>

In an assisted suicide case from Oregon that reveals some of the risk of coercion, after two doctors and a psychiatrist expressed concern that a woman was under pressure from family members and could therefore not receive a lethal prescription, a psychologist was then found who approved it, despite that psychologist being concerned that the patient's "choices may be influenced by her family's wishes and her daughter ... may be somewhat coercive."<sup>259</sup> Differences of opinion among medical professionals are not uncommon, but when coercion has been identified, and the matter is the very life of the patient, it should not be possible to proceed. The system is clearly not working when doctors are given the role of gatekeepers to ensure there is no pressure or coercion, and yet some doctors take it upon themselves to authorise a suicide in the face of such pressure and coercion, and are even prepared to state that they have done so.

Perhaps more disturbing is the fact that assisted suicide laws in the US require no evidence of consent at the actual time the lethal dose was taken. Someone may change their mind or be quite ambivalent (understandably), yet be pressured, coerced, or even forced to take the dose. In Oregon in 2019, a health care provider was only present at the time of ingestion or death in about one third of cases.<sup>260</sup>

But it is also possible that some of the pressure can come from medical professionals themselves.

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<sup>253</sup> *Ibid.*

<sup>254</sup> Lachs MS & Pillemer KA (2015) Elder Abuse. *New Engl J Med* 373(20):1947-1956.

<sup>255</sup> BBC News (2013) 'Disturbing rise' in elderly abuse reports, Age UK warns. See <https://www.bbc.com/news/uk-24399139> Accessed 13 March 2020.

<sup>256</sup> Lachs MS & Pillemer KA (2015) *Op. Cit.*

<sup>257</sup> *Ibid.*

<sup>258</sup> Chevlen E (1997) Strained Mercy. *First Things*. See <https://www.firstthings.com/article/1997/05/003-strained-mercy> Accessed 27 Mar 2020.

<sup>259</sup> Cheney K (2015) Physician-assisted suicide: A family struggles with the question of whether mom is capable of choosing to die See [https://www.oregonlive.com/health/2015/02/physician-assisted-suicide\\_a\\_f.html](https://www.oregonlive.com/health/2015/02/physician-assisted-suicide_a_f.html) Accessed 22 December 2019.

<sup>260</sup> Oregon Health Authority, Public Health Division (2020) Oregon Death With Dignity Act: 2019 Data Summary. See <https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year22.pdf> Accessed 2 April 2020.

In a review of Herbert Hendin's book, *Seduced by Death*, Eric Chevlen, a Director of Palliative Care in the US, wrote the following about his perception of what Dutch end of life culture now means for some patients.

In a society where euthanasia is widely practiced, as in Holland now, the terminally ill and disabled have learned that the public at large finds no significant value in their lives. Far from dying in dignity, these tragic souls must live their final days as objects of strained mercy at best, or simple contempt at worst. At a time when his own morale is at its lowest, when the patient is most in need of encouragement and validation, he finds himself surrounded by figures of power and authority who feel that he really ought to just hurry up and die.<sup>261</sup>

### *Disability*

The voices of people with a disability are crucial to public debate about euthanasia and assisted suicide. Individuals with a disability have often been at the forefront of advocacy for both, even though the majority of disability organisations are opposed.<sup>262</sup> People with a disability often walk a fine line between being masters of their own destiny who are free to choose like any other member of the community, and the reality of their own experiences when dealing with the discrimination and misunderstanding that so often limits that freedom.

In a seminal paper, Carol Gill has described the failure to comprehend disability rights arguments against assisted suicide, resulting in 'straw man distortions'.<sup>263</sup> Assisted suicide proponents have either missed the "complex intellectual and experience-based perspectives" of people with a disability, or sometimes deliberately sought to "strategically corrupt" such perspectives.<sup>264</sup>

Many of the key spokespersons in favor of assisted suicide are comfortable dealing in big ideas on center stage. They are familiar with ideals such as independence, control, and freedom because they are by and large from the dominant sector of society that has had access to those experiences. Diane Coleman has characterized the leading proponents of legalized assisted suicide as "white, well-off, worried, and well". They have enjoyed a good deal of control, know exactly what they have to lose, and are determined to retain it until death. Unfortunately, viewing the world from a position of privilege may limit one's insight into the consequences of a policy change whose greatest impact could fall on socially marginalized groups.<sup>265</sup>

There are several sources of pressure and influence that affect people with a disability disproportionately, so that in the end the option for assisted suicide may start to look more appealing. For people with a disability, those pressures make their choices far more complex than they might appear to others.

... what looks like autonomy on surface examination is often much more complicated and much less free.<sup>266</sup>

For example, the attitudes of some within the health professions towards people with a disability involves a value judgement that living with some disabilities must be so bad that death is a better option. Perhaps it is the commitment to wholeness that is so central to the health enterprise that makes incurability an anathema to some. This translates to the paucity of real treatment options and

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<sup>261</sup> Chevlen E (1997) *Op. Cit.*

<sup>262</sup> 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](https://ncd.gov/sites/default/files/NCD_Assisted_Suicide_Report_508.pdf) Accessed 24 November 2019.

<sup>263</sup> 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.

<sup>264</sup> *Ibid.*

<sup>265</sup> *Ibid.*

<sup>266</sup> *Ibid.*

limited access to resources that can make a huge difference. This also has traction for the families of people with a disability who may be placed in an almost impossible position by the costs of care that insurers and/or the community refuse to bear. This is not to say families will necessarily pressure their loved ones to choose euthanasia or assisted suicide, but more that people with a disability will sense the burden and lose the will to go on.

Social attitudes to disability mean that options are contracted to the extent that there really sometimes seems to be nowhere to go. Having a choice implies that there are real options. But 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”<sup>267</sup>, some will be pushed to the point that accepting assisted suicide will seem to be the best choice because to change things sufficiently to relieve those problems may either take too long or never happen at all.

If requesters [of assisted suicide] die believing that their only options are a nursing home, the degrading imposition of their intimate needs on family, taking their chances on the help of strangers, or death, how is that voluntary?<sup>268</sup>

If assisted suicide becomes the new normal, what will that do for the circumstances of disabled people?

... the establishment of assisted suicide as clinical and public policy will reinforce social conditions that contribute to disabled people’s despair.<sup>269</sup>

### *Suicide Contagion*

The Werther effect is an established phenomenon that explains the increase in suicides following a well-publicised suicide. The effect is greater when the suicide is sensationalised or otherwise framed in a positive light, or as an understandable response to particular circumstances.<sup>270</sup> To protect vulnerable members of the community, guidelines have been developed to help the media manage such reporting; for example, by the World Health Organisation (WHO).<sup>271</sup> This guidance is premised upon the broadly accepted notion that suicide should be prevented.

There is also another phenomenon, the Papageno effect, by which the converse can happen; that is, suicide numbers decline following media reporting about individuals who have adopted positive coping strategies in difficult circumstances and decided to continue living.

The possibility of a suicide-protective effect of media items on positive coping in adverse circumstances ... was empirically supported by the present findings ... Health promoting activities may be most effective when they encourage the publication of articles on individuals who refrained from adopting suicidal plans, and instead adopted positive coping mechanisms in adverse circumstances.<sup>272</sup>

The important point is that some vulnerable individuals seem to be open to suggestion in ways that others are not.<sup>273</sup> And that suggestion amounts to an influence over choosing something as critical as whether to take one’s own life. In other words, choosing suicide is not a simple rational choice by

<sup>267</sup> National Council on Disability (2019) *Op. Cit.* p47.

<sup>268</sup> Gill CJ (2010) *Op. Cit.*

<sup>269</sup> *Ibid.*

<sup>270</sup> Phillips DP (1974) The Influence of Suggestion on Suicide: Substantive and Theoretical Implications of the Werther Effect. *American Sociological Review* 39(3):340-354.

<sup>271</sup> World Health Organisation (2000) Preventing Suicide: A Resource for Media Professionals. *WHO Mental & Behavioural Disorders, Dept Mental Health*. See [https://www.who.int/mental\\_health/media/en/426.pdf](https://www.who.int/mental_health/media/en/426.pdf) Accessed 29 November 2019.

<sup>272</sup> Niederkrotenthaler T *et al.* (2010) Role of media reports in completed and prevented suicide: Werther v. Papageno effects. *Brit J Psychiatry* 197:234–243.

<sup>273</sup> Kheriaty A (2015) Social Contagion Effects of Physician-Assisted Suicide: Commentary on “How Does Legalization of Physician-Assisted Suicide Affect Rates of Suicide?” *Southern Med J* 108(10):605-606.

someone who is very clear headed about their decision. Instead it is an influenced choice, one open to something as vague as suggestibility via media, let alone pressure or coercion.

The logic underlying suicide prevention is at odds with that underlying assisted suicide. Stark puts it well:

Suicide prevention efforts rightly affirm that everyone's life matters, that people are valuable and significant, and that difficult circumstances or feelings don't change those facts. Suicide is always tragic. It is not the solution to someone's problems.

The promotion, publicity, and legalization of assisted suicide affirms something very different. It says that sometimes suicide really is the appropriate response to an individual's circumstances or anxieties. And the government and medical profession should approve and facilitate the killing of that individual. Some lives just aren't worth living.<sup>274</sup>

The Werther effect is not limited to unassisted suicides. As a phenomenon based upon suggestibility, assisted and unassisted suicides can be increased by problematic reporting of either assisted or unassisted suicides, or even perhaps by the simple fact that the publically discussed and reported arguments used for legalising assisted suicides, as noted above, contain within them the positive image of suicide that is behind the Werther effect, and countered by bodies like WHO.

Enthusiastic reporting of a double assisted suicide of a well-known couple by the group EXIT in Switzerland resulted in an increase in the rate of assisted suicides, especially of women over 65 years of age, leading to a call for media restraint because the increase was due to the Werther effect.<sup>275</sup> There seems to have been no such restraint more recently, where traditional and social media has been exploited by assisted suicide advocates in cases like that of Brittany Maynard, whose death was romanticised, arguably contributing to subsequent legal changes in some states.<sup>276</sup> Such advocacy violated almost all aspects of media guidance about suicide reporting.

Despite the theoretical rationale for a link between reporting of assisted suicide and potential increases in both assisted and unassisted suicide, empirical research is scarce. But there are some observations that raise concern. First, the number of assisted suicides in Oregon has increased year on year from 16 in 1998 to 188 in 2019, an increase of 1175%.<sup>277</sup> The reason for the increase is not entirely clear; however, something akin to a contagion effect may be responsible as assisted suicide becomes more accepted in response to media reports highlight particular cases. Second, in four states with legal assisted suicide, the rate of total suicides (assisted and unassisted) increased more than in states without such laws.<sup>278</sup> Physician assisted suicide was associated with a 6.3% increase in total suicide rates for all ages, and a 14.5% increase for those over 65 years of age.<sup>279</sup> There is also some evidence of a possible spike in assisted suicide deaths in Oregon both before and after the heavily publicised death of Brittany Maynard.<sup>280</sup> In Switzerland, where assisted suicide is permitted, the rate

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<sup>274</sup> Stark P (2016) The danger of suicide contagion--and why assisted suicide makes it worse. *National Right to Life News* p30.

<sup>275</sup> Frei A *et al.* (2003) The Werther Effect and Assisted Suicide. *Suicide & Life-Threatening Behavior* 33(2):192-200.

<sup>276</sup> Bever L (2014) How Brittany Maynard may change the right to die debate. *The Washington Post* See <https://www.washingtonpost.com/news/morning-mix/wp/2014/11/03/how-brittany-maynard-may-change-the-right-to-die-debate-after-death/> Accessed 5 February 2020.

<sup>277</sup> Oregon Health Authority, Public Health Division (2020) Oregon Death With Dignity Act: 2019 Data Summary. See <https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year22.pdf> Accessed 2 April 2020.

<sup>278</sup> Jones DA & Paton D (2015) How Does Legalization of Physician-Assisted Suicide Affect Rates of Suicide? *Southern Medical Journal* 108(10):599-604.

<sup>279</sup> *Ibid.*

<sup>280</sup> Minnesotans Against Assisted Suicide (2015) Assisted suicide and contagion. How assisted suicide advocacy and legalization threaten the lives of vulnerable people.

See [http://mnaas.org/uploads/3/7/1/2/3712413/assisted\\_suicide\\_white\\_paper\\_mnaas.pdf](http://mnaas.org/uploads/3/7/1/2/3712413/assisted_suicide_white_paper_mnaas.pdf) Accessed 26 March 2020.



of assisted suicides amongst 65 – 94 year olds doubled in men and tripled in women from 1991 to 2008.<sup>281</sup>

At the very least, traditional media and those who use social media should recognise that the positive image of assisted suicide that is promoted by right to die organisations is damaging to suicide prevention efforts. Suicide, assisted or not, involves vulnerable people who can be influenced to take their own lives, undermining autonomy. The line between assisted and unassisted suicide is very thin.

Legalizing assisted suicide means that some people who say they want to die will receive suicide intervention, while others will receive suicide assistance. The difference between these two groups of people will be their health or disability status, leading to a two-tiered system that results in death to the socially devalued group.<sup>282</sup>

### *Culture and Expectation*

Euthanasia and/or assisted suicide seem to be gaining political support throughout liberal democracies. The gradual experience of category expansion in The Netherlands now appears to be picking up pace in countries like Canada, and while the changes in the US are limited to assisted suicide, the uptake by an increasing number of states suggests that there is growing acceptance there too, at least by legislators. It is within this context that there are legitimate concerns about how legislative changes may flow to wider cultural changes about the end of life.

... it is widely acknowledged in the tradition of Anglo-American jurisprudence that the law has a pedagogical function. Laws shape the ethos of a culture by affecting cultural attitudes toward certain behaviors and influencing moral norms. In other words, the law is a teacher.<sup>283</sup>

By analogy with another moral issue at the other end of life, most liberal democracies have been living with legal abortion for many decades. Arguably, the existence of abortion laws has formed the public conscience favourably towards accepting abortion as part of the fabric of reproductive choices, even if the truth about abortion in practice has remained largely hidden from the public. Moreover, choosing abortion is often far from free. In recent years many countries have decriminalised abortion completely, removing the last vestiges of restraint to enable abortion almost entirely on demand, even if in many countries this was effectively the case already. The cultural shift towards accepting abortion took time, and there were incremental changes over many years, but in the end, an abortion culture has developed that is now embedded. Many will nevertheless completely disagree with that culture, and it is by no means unchangeable (in either direction), but the fact remains that consistent legislative changes over time have enculturated the public to abortion despite limited knowledge about its actual practice and consequences. For many, abortion has been normalised.

The grounds for that normalisation have much to do with the advancement of absolute autonomy, which is ironic because these choices are seldom free from pressure and coercion. In fact, being convinced that one is making a free choice when in fact it is coerced is one of the more effective means of enslavement to an idea. There is no need for overt pressure when one thinks the choice is one's own alone.

In relation to euthanasia and assisted suicide, in the country with the longest and broadest experience, namely The Netherlands, the leading edge of the expression of absolute autonomy must surely come within the category of being tired of life.<sup>284</sup> Euthanasia for being tired of life would

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<sup>281</sup> Steck N *et al.* (2015) Time-trends in assisted and unassisted suicides completed with different methods: Swiss National Cohort. *Swiss Med Wkly* 145:w14153.

<sup>282</sup> Coleman D (2002) Not Dead Yet. In: *The Case against Assisted Suicide. For the Right to End-of-Life Care*. Eds Foley K & Hendin H, John Hopkins University Press, Baltimore, 221.

<sup>283</sup> Kheriaty A (2015) *Op. Cit.*

<sup>284</sup> Florijn BW (2018) Extending euthanasia to those 'tired of living' in the Netherlands could jeopardize a well-functioning practice of physicians' assessment of a patient's request for death. *Health Policy* 122:315-319.

require no other reason than being over the age of 70 and having a ‘completed life’, or being ‘tired of life’. The Dutch government believes that “... the euthanasia request for older people who *no* longer have any *life* perspective, is a legitimate request”<sup>285</sup>, and in 2010 support from the Dutch public for a vignette involving physician-assisted suicide for a ‘tired of life’ case was 26%.<sup>286</sup> Support from elderly Dutch people was higher (45% in 2008), having risen from 31% in 2001 and 33% in 2005; and for euthanasia rather than assisted suicide, the figures were higher still – 58% in 2001, 64% in 2005, and 70% in 2010.<sup>287</sup> At approximately the same time (2011/2012), 27% of physicians could conceive of granting a request for euthanasia or assisted suicide from a patient who was tired of life.<sup>288</sup>

For those Dutch citizens who feel that their life is completed, what are the main reasons that might drive them to consider either euthanasia or assisted suicide? A study by van Wijngaarden *et al.* in 2013 explored the reasons in depth. The primary finding was that these particular elderly people experienced disconnection between their actual lives and what they desired. The authors describe this as “a tangle of inability and unwillingness to connect to one’s actual life”.<sup>289</sup> More specifically, participants described their reasons as follows: a sense of aching loneliness; the pain of not mattering; the inability to express oneself; multidimensional tiredness; and, a sense of aversion towards feared dependence. Rather than the desire for death being solely an opportunity to express “independence and autonomy”, the desire was “strongly influenced by fears, sadness and loneliness”.

While the population under research as much as possible wants to run their own affairs without interference from others, paradoxically the findings simultaneously indicate [the] elderly to be highly dependent on others when it comes to their well-being. They are driven by a strong human desire to be visible, recognized, wanted, needed, valued, depended upon, or attended to by others.<sup>290</sup>

Hence, the desire for death was at least in part a response to external factors that operated as an influence, a modulator of choice, a pressure connected to the failure to find meaning.

Herein lies the concern – if the community establishes the provision of death on demand as normal practice, how will that *not* become a cultural expectation for elderly isolated, lonely, and unwanted souls.

What may be a firm wish for one person could easily translate to an expectation to ‘do the right thing’ for another. Van Wijngaarden and colleagues argue that such a culture would “increase social pressure on older people and reinforce negative ideas surrounding old age”.<sup>291</sup> Moreover, assisted dying as a solution to alienation, loneliness, and meaninglessness, strips away the incentive to positively address such problems and attempt to bring meaning to people in that predicament. It risks building a community that does not care. Meaninglessness, alienation, and fear cause suffering that demands a response, but since suffering like this is part of all human existence at one time or another, will our capacity to deal with it be compromised by euthanasia?

Professor Theo Boer was a former member of one of the Dutch regional committees charged with regulating euthanasia and assisted suicide. He originally supported the 2002 euthanasia legislation, but then changed his perspective. One of his main concerns is the development of a euthanasia culture.

We’re getting used to euthanasia, that is exactly what should not happen. We’re no longer speaking about the exceptional situations that the law was created for, but a

<sup>285</sup> *Ibid.*

<sup>286</sup> Raijmakers NJH *et al.* (2015) Assistance in dying for older people without a serious medical condition who have a wish to die: a national cross-sectional survey. *J Med Ethics* 41:145-150.

<sup>287</sup> Buiting HM *et al.* (2012) Older peoples’ attitudes towards euthanasia and an end-of-life pill in The Netherlands: 2001-2009. *J Med Ethics* 38:267-273.

<sup>288</sup> Bolt EE *et al.* (2015) *Op. Cit.*

<sup>289</sup> van Wijngaarden E *et al.* (2015) Ready to give up on life: The lived experience of elderly people who feel life is completed and no longer worth living. *Social Science & Medicine* 138:257-264.

<sup>290</sup> *Ibid.*

<sup>291</sup> van Wijngaarden E *et al.* (2017) Assisted dying for healthy older people: a step too far? *BMJ* 357:j2298.

gradual process towards organised death. It is not good for society to have organised death facilitated by the state. A culture of euthanasia undermines our capacity to deal with suffering, and that is very bad for society.<sup>292</sup>

A society that enshrines the value of death as a solution to suffering, and even the sorrows and distresses of life, will be one that simply cannot allow people to make their own choices. Choices will end up being made for some and shaped for others around an ideal that honours only certain characteristics and experiences as archetypal for humanity. Broken humanity will be less tolerated, we will have hardened ourselves, and the more noble side of human nature will have been degraded.

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<sup>292</sup> Sherwood H (2018) A woman's final Facebook message before euthanasia: 'I'm ready for my trip now...' *The Guardian Australian Ed.* See <https://www.theguardian.com/society/2018/mar/17/assisted-dying-euthanasia-netherlands> Accessed 21 January 2020.



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