

**Submission  
No 21**

**INQUIRY INTO PROVISIONS OF THE VOLUNTARY  
ASSISTED DYING BILL 2021**

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# Submission to the NSW Parliament Standing Committee on Law and Justice regarding the Voluntary Assisted Dying Bill 2021

Dr Gregory K Pike, Director, Adelaide Centre for Bioethics and Culture, November 2021

Thank you for this opportunity to make a submission regarding such a critical issue.

The ABC ran a lead story on November 11<sup>th</sup> this year which began “When Paul Keating speaks it pays to listen ...”.<sup>1</sup> Although the article was about something else, respect for someone of his stature suggests it would be wise to listen to what he has to say about euthanasia. At the height of public debate surrounding euthanasia in the Victorian Parliament, Paul Keating wrote an article that captured the essence of why euthanasia represents a fundamental departure from one of the core principles of ethics - that innocent human life should never be intentionally terminated. Euthanasia also undermines a central tenet of civil society – that the role of the law is to protect all members impartially.

“No matter what justifications are offered for the bill, it constitutes an unacceptable departure in our approach to human existence and the irrevocable sanctity that should govern our understanding of what it means to be human ... It stands for everything a truly civil society should stand against.”<sup>2</sup>

This Bill crosses a Rubicon that will damage the culture of dying in perpetuity. It will change how the vulnerable are viewed and treated. In the longer term, the *in principle* position that some lives are not worth living will be impossible to limit to voluntary request. The evidence from other legislatures is clear – what starts as voluntary inevitably becomes involuntary.<sup>3</sup> Suspension of the foundational right to life of some, even on request, puts all at risk. And even what we might think is voluntary becomes less so as the vulnerable feel the pressure for an early departure.

Principles matter. Keating again – “They define the norms and values of a society and in this case the principles concern our view of human life itself”. Everything flows from key defining principles. Change the crucial values, and behaviours and practices all shift to align with that change. And the key change in values with euthanasia is that some lives are not worth living.

Advocacy for euthanasia inevitably focuses on the rare hard cases. The sponsor of this Bill argues that euthanasia would be for those who otherwise would experience a “cruel agonising death”, because they are experiencing unbearable pain and suffering.<sup>4</sup> Besides listening to palliative care specialists who say for such rare cases palliative sedation is a valid option, we can look to places where euthanasia is legal to see whether it is in practice only for cases like these.

In short, what does the existing evidence tell us will likely happen if NSW goes down this path?

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<sup>1</sup> Grant S (2021) Paul Keating's Press Club speech raises important questions about Australia's relationship with China. *ABC News*. See <https://www.abc.net.au/news/2021-11-11/paul-keating-press-club-china-australia-relationship/100609826> Accessed 11 Nov 2021.

<sup>2</sup> Keating P (2017) Paul Keating: Voluntary euthanasia is a threshold moment for Australia, and one we should not cross. *Sydney Morning Herald*, see <https://www.smh.com.au/opinion/paul-keating-voluntary-euthanasia-is-a-threshold-moment-for-australia-and-one-we-should-not-cross-20171019-gz412h.html> Accessed 2 Jun 2021.

<sup>3</sup> Pike GK (2020) Euthanasia and Assisted Suicide – When Choice is an Illusion and Informed Consent Fails. *Bios Centre*, London. See <https://bioscentre.org/articles/euthanasia-and-assisted-suicide-when-choice-is-an-illusion-and-informed-consent-fails/> Accessed 10 Jun 2021.

<sup>4</sup> Greenwich A (2021) Voluntary Assisted Dying Bill 2021, Second Reading Speech. See [https://www.alexgreenwich.com/vad\\_bill\\_2021\\_2nd\\_read](https://www.alexgreenwich.com/vad_bill_2021_2nd_read) Accessed 11 Nov 2021.

## Crossing the Rubicon

Because defining principles guide the formation of laws in a civil society, when they change there are flow on effects. In the context of legal euthanasia, the foundational right to life of all members of the community is substituted for two key principles. First, that death is a benefit; and second, that autonomy trumps other principles. On the basis of that realignment, it is unsurprising to observe what has happened in Holland and Belgium for example.

Despite a stated commitment to voluntary choice, when death is seen as a benefit, it soon becomes possible for someone else to decide that death is appropriate for those who have not requested it, either directly in cases of non-voluntary euthanasia, or indirectly via coercion, pressure and influence.

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'.<sup>5</sup> However, the same reports show that many more patients were overdosed with opioids explicitly to end life, approximately 40% of whom made no request.<sup>6</sup> There has been a steady and large increase in deaths within this category from 2001 to 2015 (20% to 36% respectively),<sup>7</sup> 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 almost certainly 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.

Infants clearly cannot make a voluntary choice to have their lives terminated. In Dutch and Belgian reports up till 2010, between 7% and 9% of all infant deaths involved active euthanasia, that is, a lethal injection.<sup>8,9</sup> 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.<sup>10</sup>

Euthanasia of dementia patients, whose voluntary choices are limited or absent, has been increasing in Holland – from 12 in 2009 to 169 in 2017.<sup>11,12</sup> 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),<sup>13</sup> 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'.<sup>14,15</sup> While no equivalent research exists for Holland it is likely that something similar pertains.

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<sup>5</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>6</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>7</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>8</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>9</sup> Provoost V *et al.* (2005) Medical end-of-life decisions in neonates and infants in Flanders. *Lancet* 365:1315-1320.

<sup>10</sup> Ten Cate K *et al.* (2015) *Op. Cit.*

<sup>11</sup> de Beaufort ID & van de Vathorst S (2016) Dementia and assisted suicide and euthanasia. *J Neurol* 263:1463-1467.

<sup>12</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>13</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>14</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>15</sup> Chambaere K *et al.* (2010) Physician-assisted deaths under the euthanasia law in Belgium: a population-based survey. *Can Med Assoc J* 182(9):895-901.

Whether psychiatric patients can make a genuine informed choice for euthanasia is controversial, and yet such cases have steadily risen in both Holland and Belgium. In Holland the numbers have increased from 0 in 2008 to 83 in 2017.<sup>16</sup> Cases include for depressive disorders, personality disorders, psychosis, post-traumatic stress or anxiety, eating disorders, substance abuse, prolonged grief, and autism.<sup>17</sup> 70% are women. The increasing incidence is similar in Belgium. Here are some examples of psychiatric euthanasia cases from the notes of attending physicians:

The patient indicated that she had had a life without love and therefore had no right to exist (case 2012-46).<sup>18</sup>

The patient was an utterly lonely man whose life had been a failure (case 2013-21).<sup>19</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>20</sup>

These examples where death as a benefit predominates sit somewhat in contrast to cases where voluntarism predominates. It is almost as if death as a benefit and voluntarism can be interchangeably emphasised depending on who the operator is.

Where a voluntary choice can be made, does the evidence show that those who choose euthanasia are indeed in unbearable pain and agony? If not then it should be acknowledged that this Bill will lead to something else, just as has happened elsewhere. Like other legislation in Australia, this Bill cannot confine euthanasia to such cases. The phrase at 16(d)(iii) requires that a person's condition "is causing suffering to the person that cannot be relieved in a way the person considers tolerable". This speaks for itself in terms of the breadth of subjective experience it permits. It would include psychological and existential suffering.

In the most recent report from Canada, the main two reasons for choosing euthanasia were "Loss of ability to engage in meaningful activities" and "Loss of ability to perform activities of daily living".<sup>21</sup> Reference to pain was difficult to unravel because the wording chosen was "Inadequate control of pain (or concern)", cited in 57.4% of cases. This figure therefore includes those *concerned* about pain, rather than experiencing it. And for those who were experiencing pain, there was no way to know its severity.

In Oregon in 2020, the main 4 reasons cited by those who received assisted suicide were "less able to engage in activities making life enjoyable" (94.3%); "losing autonomy" (93.1%), "loss of dignity" (71.8%) and "burden on family, friends/caregivers" (53.1%). "Inadequate pain control, or concern about it" was cited by 32.7%.

It is time to give up the pretence that euthanasia and assisted suicide are all about unbearable pain. This is not to say such cases don't exist, but rather that they are extremely rare and where euthanasia and assisted suicide are legal, it is rarely personally cited as the experience of those who choose to end their lives.

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<sup>16</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>17</sup> 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>18</sup> Dutch recipient of euthanasia or assisted suicide. Cited by Kim SYH *et al.* (2016) *Op. Cit.*.

<sup>19</sup> *Ibid.*

<sup>20</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>21</sup> Health Canada (2021) Second annual report on medical assistance in dying in Canada 2020. See <https://www.canada.ca/content/dam/hc-sc/documents/services/medical-assistance-dying/annual-report-2020/annual-report-2020-eng.pdf> Accessed 10 Nov 2021.

The consistent finding that people requesting euthanasia or assisted suicide do so because they perceive themselves to be a burden to others bears some scrutiny. Despite the fact that some key figures in authority have argued euthanasia should be chosen by those who see themselves as a burden<sup>22</sup>, in fact patients don't really need any encouragement. They 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>23</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>24</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>25,26</sup>

Surely the response to someone who feels they are burdening others is not to simply acquiesce but to encourage them, to reassure them of their worth, and that burden is to be shared because they are valued?

... 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>27</sup>

Just as perceived burdensomeness contracts choices or conditions them, having a disability similarly limits choice and forces some people to consider what they would rather not.

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>28</sup>, some will be pushed to the point that accepting euthanasia or 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>29</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

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<sup>22</sup> "... if somebody absolutely, desperately wants to die because they're a burden to their family, or the state, then I think they too should be allowed to die. Actually, I've just written an article called 'A Duty to Die?' for a Norwegian periodical. I wrote it really suggesting that there's nothing wrong with feeling you ought to do so for the sake of others as well as yourself." Warnock Baroness BM (2008) Dementia sufferers may have a "duty to die." *Telegraph*. See <http://www.telegraph.co.uk/news/uknews/2983652/Baroness-Warnock-Dementia-sufferers-may-have-a-duty-to-die.html>. Accessed 20 Mar 2020.

<sup>23</sup> Blendon RJ *et al.* (1992) Should Physicians Aid Their Patients in Dying? The Public Perspective. *JAMA* 267(19):2658-2662.

<sup>24</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>25</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>26</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>27</sup> Jecker NS (2014) Against a Duty to Die. *Am Med Soc J Ethics* 16(5):390-394.

<sup>28</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>29</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.

conditions that contribute to disabled people's despair.<sup>30</sup>

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>31</sup>

The logical extension of 'voluntary choice' for death is to do away altogether with limits like terminality, progressive disease, or physical or mental pain. This is the threshold upon which the Dutch now tread.

This leading edge of the expression of the primacy of autonomy comes within the category of being tired of life.<sup>32</sup> Euthanasia for being tired of life would 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>33</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>34</sup> Support from elderly Dutch people for euthanasia was 70% in 2010.<sup>35</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>36</sup>

What a transformation in the culture surrounding death and dying this exemplifies!

One can be sure that anyone in the early years of the Dutch experiment who might have suggested it would get to this would be summarily dismissed or ridiculed or both. Do we really think it would be any different here as we follow the same logic and gradually allow the shift in values inherent in this Bill to permeate our collective psyche?

Perhaps euthanasia activist Philip Nitschke will finally succeed in his wish for a 'peaceful pill' for "the depressed, the elderly bereaved, the troubled teen."<sup>37</sup>

Hopefully, we will not look back one day at this Bill as the first step towards that end.

In conclusion, the main emphasis of this submission has been to argue that this Bill should be rejected because it will shape how the community deals with suffering by putting the lives of many vulnerable people at serious risk. In the longer term we will become less tolerant of those who suffer and no longer see them as valued members of the community who we might assist in their struggle.

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<sup>30</sup> *Ibid.*

<sup>31</sup> Chevlen E (1997) Strained Mercy. *First Things*. See <https://www.firstthings.com/article/1997/05/003-strained-mercy> Accessed 27 Mar 2020.

<sup>32</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.

<sup>33</sup> *Ibid.*

<sup>34</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>35</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>36</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>37</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

Perhaps the whole community might compromise its search for meaning amidst the suffering that is so common to the experience of so many at one time or another.

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.<sup>38</sup>

### *A Note on the Northern Territory*

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

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

Pain was not a prominent clinical issue in our study. Fatigue, frailty, depression and other symptoms contributed more to the suffering of patients.<sup>39</sup>

The cases do not fit the publicly portrayed archetypal case for euthanasia; that is, at death's door, in terrible pain, and with no prospect for treatment or recovery.

The journal article, even though a precise and dispassionate evaluation of the seven cases, makes for sad reading. ROTTI and its implementation was effectively a statement that some lives are not worth living. Genuine care in the form of good medical practice could have made all the difference, but instead there was tacit agreement that death was the solution.

These were vulnerable people. Their decisions were voluntary but given the disagreement among medical professionals about their condition, untreated depression despite psychiatric involvement, lack of social support, and limited palliative care options, whether they made a *genuinely informed choice* is another matter entirely.

It is also noteworthy that Indigenous opposition to ROTTI was authoritatively reported to be "near universal", and that,

... the very fact of the legislation, at least anecdotally, is causing people to be reluctant to present, or to present not as soon as one might, to attend clinics or to go to hospital.<sup>40</sup>

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<sup>38</sup> Pike GK (2020) *Op. Cit.*

<sup>39</sup> Kissane D *et al.*, Seven deaths in Darwin: case studies under the Rights of the Terminally Ill Act, Northern Territory, Australia. *The Lancet* 352:1097-1102, 1998.

<sup>40</sup> Senate Legal and Constitutional Legislation Committee, *Euthanasia Laws Bill 1996*, March 1997, 47.