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WHO IS ELIGIBLE FOR VOLUNTARY ASSISTED DYING? NINE MEDICAL CONDITIONS ASSESSED AGAINST FIVE LEGAL FRAMEWORKS

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ABSTRACT

Eligibility criteria in voluntary assisted dying legislation determine access to assistance to die. This paper undertakes the practical exercise of analysing whether each of the following nine medical conditions can provide an individual with access to voluntary assisted dying: cancer, motor neurone disease, chronic obstructive pulmonary disease, chronic kidney disease, Alzheimer's disease, anorexia, frailty, spinal cord injury and Huntington's disease. This analysis occurs across five legal frameworks: Victoria, Western Australia, a model Bill in Australia, Oregon and Canada. The paper argues that it is critical to evaluate voluntary assisted dying legislation in relation to key medical conditions to determine the law's boundaries and operation. A key finding is that some frameworks tended to grant the same access to voluntary assisted dying, despite having different eligibility criteria. The paper concludes with broader regulatory insights for designing voluntary assisted dying frameworks both for jurisdictions considering reform and those reviewing existing legislation.

I INTRODUCTION

A key challenge for regulators designing a voluntary assisted dying ('VAD') system is to determine who can access to VAD and in what circumstances. The primary mechanism to control access is the eligibility criteria in VAD legislation. In the first paper in this two-part series,[2] we undertook a critical and comparative analysis of eligibility criteria in five VAD frameworks. The Australian frameworks considered were: the *Voluntary Assisted Dying Act 2017* (Vic) ('Victorian Act'); the *Voluntary Assisted Dying Act 2019* (WA) ('WA Act'); and a model Voluntary Assisted Dying Bill 2019 ('model Bill')[3] drafted for consideration by other Australian states and recommended by the Queensland Parliamentary inquiry considering VAD as the proposed basis for reform.[4] The international models were Oregon's *Death with Dignity Act 1994* ('Oregon Act')[5] and Canada's *Criminal Code* ('Canadian *Criminal Code*')[6]. A

[2] Ben P White et al, 'Comparative and Critical Analysis of Key Eligibility Criteria for Voluntary Assisted Dying Under Five Legal Frameworks' (2020) (forthcoming) ('Comparative and Critical Analysis of Key Eligibility Criteria for VAD').

[3] The model Bill was drafted by two of the authors: Ben White and Lindy Willmott, 'Voluntary Assisted Dying Bill 2019' (Model Bill, Australian Centre for Health Law Research, Faculty of Law, Queensland University of Technology, April 2019) https://eprints.qut.edu.au/128753/. The model Bill was subsequently published as Ben White and Lindy Willmott, 'A Model Voluntary Assisted Dying Bill' (2019) 7(2) *Griffith Journal of Law and Human Dignity* 1 ('model Bill').

[4] Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee, Parliament of Queensland, *Inquiry into Aged Care, End-of-Life and Palliative Care and Voluntary Assisted Dying* (Report No 34, 31 March 2020) 105, 'Recommendation 1' ('*Queensland Parliamentary Report*').

[5] *Death with Dignity Act*, Or Rev Stat §§ 127.800–127.995 (1994) ('*Oregon Act*').

[6] *Criminal Code*, RSC 1985, c C-46, ss 241.1–241.4 ('Canadian *Criminal Code*'). Until recently, the Canadian *Criminal Code* (n 6) prohibited all forms of assisted dying. In 2015, the blanket prohibition was found to violate the Canadian *Charter of Rights and Freedoms* ('*Charter*') and struck down by the Supreme Court of Canada (*Carter v. Canada (Attorney General)* [2015] 1 SCR 331). In 2016, the federal Parliament passed legislation (*An Act to Amend the Criminal Code and to make related amendments to other Acts (Medical Assistance in Dying),* SC 2016 ('Bill C-14')) to amend the *Criminal Code* to make it consistent with the *Charter* and provide a regulatory framework for MAiD. In 2019, a Quebec court found that Bill C-14's 'reasonably foreseeable' eligibility criterion violated the *Charter* and struck it down (*Truchon v. Canada (Attorney General)* [2019] QCCS 3792). In 2021, the Canadian *Criminal Code* was further amended through *An Act to Amend the Criminal Code (Medical Assistance in Dying),* SC 2021 <https://parl.ca/DocumentViewer/en/43-2/bill/C-7/royal-assent> ('Bill C-7'). Amendments of particular relevance for this paper include: removing the eligibility criterion 'natural death has become reasonably foreseeable'; adding a two year blanket exclusion of access for persons with mental illness as their sole underlying medical condition (in force until 17 March 2023); and permitting VAD to be provided to someone after they have lost decision-making capacity if, before losing capacity but after having been found to be eligible for VAD and after their death has become reasonably foreseeable, they came

comparative analysis of these criteria across the five selected regimes demonstrated many similarities but also significant differences in who would be eligible to access VAD. The paper concluded with implications of these analyses, from a regulatory perspective, for designing VAD legislation.

This second paper addresses more practical implications. Drawing on the earlier legal analysis, it considers the *application* of the eligibility criteria from those five frameworks to nine medical conditions. It considers whether a person with any of those particular medical conditions may be eligible for VAD under the frameworks and, if so, at what point in their condition's trajectory. The concrete application of these eligibility criteria to medical conditions is critical to determine a VAD law's boundaries in practice. As this paper demonstrates, changes in framing of eligibility criteria in the different jurisdictions can affect access to VAD, and at what stage in a person's medical condition access might be possible.

The nine medical conditions considered were: cancer (specifically colorectal cancer),[7] motor neurone disease ('MND'), chronic obstructive pulmonary disease ('COPD'), chronic kidney disease ('CKD'), dementia (specifically Alzheimer's disease),[8] anorexia, frailty, spinal cord injury ('SCI') and Huntington's disease. These conditions were chosen to illustrate how various eligibility criteria would apply to a diverse range of conditions. It was not feasible to examine all possible medical conditions, so our starting point was the typical conditions for which VAD is sought in Victoria, Oregon, and Canada (the three jurisdictions considered

to a written arrangement with their VAD provider to provide VAD after they lose decision-making capacity ('final consent waiver').

[7] To facilitate detailed engagement with the VAD eligibility criteria, it was necessary to select one particular kind of cancer, given the variation in nature and trajectory of different kinds of cancer.

[8] As was for cancer, it was necessary to consider one particular type of dementia to facilitate detailed engagement with the VAD eligibility criteria.

where VAD is available).[9] Data from Oregon and Canada on deaths due to VAD demonstrate the three most common underlying conditions are cancer,[10] neurological conditions (including MND)[11] and respiratory conditions (such as COPD).[12] There are only very limited publicly-reported data on VAD deaths in Victoria (due to privacy concerns) but those which are reported are consistent with the two international jurisdictions: cancer (78%), neurodegenerative diseases (15%) and 'other' diseases (7%), with listed examples of these other diseases including respiratory conditions such as COPD.[13] Anecdotal reports about the Victorian system also suggest cancer, neurological disease and respiratory conditions are the most prevalent conditions.[14] However, considering only conditions for which VAD is commonly sought would not explore the potential boundaries of the legislation for other

[9] The *Voluntary Assisted Dying Act 2019* (WA) ('*WA Act*') will not commence until mid-2021: 'Voluntary Assisted Dying', *Government of Western Australia, Department of Health* (Webpage, 3 April 2020) <https://ww2.health.wa.gov.au/voluntaryassisteddying>. The model Bill is not operational.

[10] In Oregon in 2019, 68% of deaths due to VAD involved people with cancer: Oregon Health Authority, *Oregon Death with Dignity Act 2019 Data Summary* (Report, 25 February 2020), 6, 10–11 ('*Oregon Data Summary*'). In Canada in 2018, the figure was 67.2%: Health Canada*, First Annual Report on Medical Assistance in Dying in Canada 2019* (Report, July 2020), 22 ('*Canadian First Annual Report*').

[11] In Oregon in 2019, neurological disease accounted for 14% of VAD deaths, with 10% from MND alone: *Oregon Data Summary* (n 10) 10–11. In Canada in 2019, 10.4% of VAD deaths involved people with neurodegenerative conditions: *Canadian First Annual Report* (n 10) 22.

[12] In Oregon in 2019, 7% of VAD deaths involved people with respiratory disease: *Oregon Data Summary* (n 10) 10–11. Canada's statistics indicate 10.8% of VAD deaths involved respiratory conditions: *Canadian First Annual Report* (n 10) 22.

[13] Voluntary Assisted Dying Review Board, Victoria State Government, *Report of Operations: January to June 2020* (Report, August 2020) contains very limited data concerning the medical condition of people accessing VAD. In addition to the above data, the only other significant information provided is a break-down of cancer data into the four most common types of cancer for which VAD deaths occurred (but not for colorectal cancer which is considered later). As a result, the Board VAD data is not discussed further.

[14] An oncologist involved in numerous VAD applications estimates at least 70% of cases of VAD in Victoria involve people with cancer: Cameron McLaren, 'An Update on VAD: (Almost) A Year in Review', *Dying with Dignity Victoria* (online, 16 June 2020) <https://www.dwdv.org.au/sb_cache/associationnews/id/122/f/One_Year_of_VAD-Dr_Cameron_McLaren.pdf, 3>. Another Victorian GP who has provided VAD states that after one year in operation, 'Cancer has been the most common reason, then neurological disorders like motor neurone disease, with some cardiovascular and respiratory diseases': Nick Carr, 'Choosing When to Go: What the Nation Can Learn from Victoria's Embrace of Voluntary Assisted Dying', *Crikey* (online, 18 June 2020) <https://www.crikey.com.au/2020/06/18/voluntary-assisted-dying-laws-one-year-on/>. One family's story confirms at least one Victorian with MND died from VAD in the first six months that the *Voluntary Assisted Dying Act 2017* (Vic) ('*Victorian Act*') was operational: Bridget Rollason and Mary Gearin, 'More than 130 Victorians Apply to End their Lives in First Six Months of State's Assisted Dying Laws' *ABC News* (online, 19 February 2020) <https://www.abc.net.au/news/2020-02-19/assisted-dying-laws-victoria-used-by-more-than-50-people/11979962>.

conditions and would be a self-limiting approach. Therefore, we also examined conditions for which people were accessing VAD in more permissive regimes such as the Netherlands and Belgium[15] and Canada.[16] We also included medical conditions discussed in VAD literature,[17] including those described as controversial, such as Alzheimer's disease[18] and one kind of mental illness, anorexia.[19] The resulting list, therefore, included not only typical

[15] As noted in the first paper in this series, these jurisdictions are not included in this paper because their laws operate within quite different legal systems and they are culturally more distinct from Australia than other common law countries: White et al, 'Comparative and Critical Analysis of Key Eligibility Criteria for VAD' (n 2).
[16] Canada is one of the most permissive VAD regimes and a shared legal heritage makes Canada a natural comparator for Australia here.
[17] Jocelyn Downie and Kate Scallion, 'Foreseeably Unclear: The Meaning of the "Reasonably Foreseeable" Criterion for Access to Medical Assistance in Dying in Canada' (2018) 41(1) *Dalhousie Law Journal* 23. See also Jocelyn Downie and Jennifer A. Chandler, *Interpreting Canada's Medical Assistance in Dying Legislation* (IRPP Report, 1 March 2018) ('*IRPP Report*').
[18] VAD for people with dementia is possible, for example, in the Netherlands and Belgium: Dominic R Mangino et al, 'Euthanasia and Assisted Suicide of Persons with Dementia in the Netherlands' (2020) 28(4) *American Journal of Geriatric Psychiatry* 466; Sigrid Dierickx et al, 'Euthanasia for People with Psychiatric Disorders or Dementia in Belgium: Analysis of Officially Reported Cases' (2017) 17(1) *BMC Psychiatry* 203. For a systematic review of public attitudes, and the attitudes of health professionals and individuals with dementia, see Emily Tomlinson and Joshua Stott, 'Assisted Dying in Dementia: A Systematic Review of the International Literature on the Attitudes of Health Professionals, Patients, Carers and the Public, and the Factors Associated With These' (2015) 30(1) *International Journal of Geriatric Psychiatry* 10. For some ethical arguments on the issue, see Paul T Menzel and Bonnie Steinbock, 'Advance Directives, Dementia, and Physician-Assisted Death' (2013) 41(2) *Journal of Law, Medicine and Ethics* 484; Inez D de Beaufort and Suzanne van de Vathorst, 'Dementia and Assisted Suicide and Euthanasia' (2016) 263(7) *Journal of Neurology* 1463. For a discussion of the recent prosecution in the Netherlands for VAD for a person with dementia, see Eva Constance Alida Asscher and Suzanne van de Vathorst, 'First prosecution of a Dutch doctor since the Euthanasia Act of 2002: what does the verdict mean?' (2020) 46 *Journal of Medical Ethics* 71. The Canadian *Criminal Code* (n 6) allows access to VAD for some individuals with dementia (those who still have decision-making capacity and those who have lost it). Jocelyn Downie and Stefanie Green, 'For people with dementia, changes in MAiD law offer new hope' (2021) *Policy Options* <https://policyoptions.irpp.org/magazines/april-2021/for-people-with-dementia-changes-in-maid-law-offer-new-hope/>.
[19] VAD is permissible for people with mental illness who meet the other eligibility criteria in the Netherlands and Belgium: Scott Y H Kim, Raymond G De Vries and John R Peteet, 'Euthanasia and Assisted Suicide of Patients with Psychiatric Disorders in the Netherlands 2011 to 2014' (2016) 73(4) *JAMA Psychiatry* 362; Dierickx et al (n 18). The use of VAD for mental illness remains controversial: see, for example, Brendan Kelly and Declan McLoughlin, 'Euthanasia, Assisted Suicide and Psychiatry: A Pandora's Box' (2002) 181(4) *British Journal of Psychiatry* 278; Kathleen Sheehan, K Sonu Gaind and James Downar, 'Medical Assistance in Dying: Special Issues for Patients with Mental Illness' (2017) 30(1) *Current Opinion in Psychiatry* 26. The Canadian *Criminal Code* permits VAD for people with mental illness so long as they also have a serious and incurable physical illness, disease, or disability. The *Criminal Code* explicitly states that mental illness is not considered to be a serious and incurable illness, disease, or disability for the purposes of establishing eligibility: Canadian *Criminal Code* (n 6), s 241.2(2.1). However, this exclusion will be automatically repealed on 17 March 2023, due to a 'sunset clause' set out in Bill C-7 (n 6) cl 6, enacted to enable the federal government to have time to commission an independent expert panel to conduct a review and make recommendations regarding protocols, guidance and safeguards for MAiD for persons with mental illness, and to allow provincial and territorial governments time to prepare for 2023: Government of Canada, 'About Mental Illness and MAiD', Medical Assistance in Dying (webpage, 18 March 2021) <https://www.canada.ca/en/health-canada/services/medical-assistance-dying.html>.

conditions when VAD is permitted but also conditions that help determine boundaries of VAD frameworks.

These nine conditions are structured using the Australian models as a departure point. Section 2 considers medical conditions where access to VAD is possible (or even likely, such as for cancer), but may depend on prognosis or illness trajectory (such as for COPD). Section 3 then considers medical conditions for which access to VAD is either clearly not permitted or very unlikely under Australian models. Examples include Alzheimer's and Huntington's diseases. Section 4 explores similarities and differences across models and considers the effects of differently drafted eligibility criteria. Sections 5 and 6 discuss implications for regulators and policy-makers designing VAD regulation.

This paper, like the previous paper, focuses on the eligibility criteria most relevant to the person's medical condition. This includes criteria dealing with the nature of the condition such as, for example, whether it needs to be incurable, advanced or progressive or likely to cause death (and, if so, within a specified period). It also includes the requirement for decision-making capacity, which is important because various medical conditions can have implications for a person's capacity.

The paper does not consider other criteria unrelated to medical conditions, such as age and residency, and presumes they are met. The paper also does not consider criteria about patient suffering. While suffering is linked to the nature of a medical condition, in all jurisdictions analysed, 'suffering' is assessed subjectively, that is, by the person seeking VAD.[20] Because 'suffering' is an individual experience, one person may experience the

[20] See, eg, *Victorian Act* (n 14) s 9(1)(d)(iv); *WA Act* (n 9) s 16(1)(c)(iii).

requisite suffering for one medical condition but may not for another condition. Likewise, one person with a particular medical condition may be suffering but another person in an identical medical state may not. As such, it is not possible to exclude or include a particular condition as being *capable* of satisfying the VAD criteria on the basis of the 'suffering' criterion.

This paper adopts terminology used in the Victorian Act[21] (subsequently mirrored in the WA Act[22] and model Bill[23]). VAD therefore includes both 'self-administration'[24] and 'practitioner administration'[25]. 'Medical condition' refers broadly to any condition caused by disease, illness, disability, or injury, although we note some VAD laws specifically address these latter concepts.

Finally, we note the limitation that this analysis considers only whether a medical condition is *capable* of providing access to VAD. Whether or not a specific person would qualify depends not only on their condition, but also its progression when seeking access, whether treatments are available (and acceptable to the person), and whether they meet the other eligibility criteria. Further, we acknowledge that clinical characterisation of some conditions described may be contentious. For example, whether or not a condition should be regarded as incurable may be disputed. The paper outlines our views on each medical condition, informed by the expertise of our clinical authors, and considers how that condition may typically affect a person seeking access to VAD. But in all cases, access to VAD will depend

[21] *Victorian Act* (n 14).
[22] *WA Act* (n 9).
[23] Model Bill (n 3).
[24] The person takes the prescribed medication themselves; sometimes this is called physician-assisted suicide or physician-assisted dying.
[25] The person is administered the medication by a doctor, or nurse practitioner in Western Australia or Canada; sometimes this is called voluntary euthanasia.

on an individual assessment of a person in relation to relevant eligibility criteria. It is possible that a person with a condition which would generally provide access to VAD is ineligible; it is also possible that a person with a condition generally not providing access to VAD meets the relevant criteria.

II MEDICAL CONDITIONS FOR WHICH ACCESS TO VAD IS POSSIBLE UNDER ALL FRAMEWORKS

A *Colorectal Cancer*

1 *Nature of Condition*

Many cancers may make a person eligible for VAD. Colorectal cancer was selected as an example because it is the second most common cause of cancer in both men and women in Australia (after prostate cancer for men and breast cancer for women) and can cause death.[26] The severity of the disease varies depending on the extent to which it has spread. Stage I disease, where the tumour is confined to the bowel wall, has a 90% survival rate and low risk of recurrence when treated in accordance with current clinical guidance.[27] If diagnosed later, the tumour may have invaded the bowel wall (Stage II), and/or metastasised to lymph nodes (Stage III). This may progress to metastases in other parts of the body (Stage IV), which has a 13% five-year relative survival rate in Australia.[28] Treatment options depend on the extent of disease. The majority of people with extensive metastatic

[26] Australian Government, Australian Institute of Health and Welfare, 'Cancer in Australia 2019' (Media Release, Cancer Series No 119, Catalogue No CAN 123, 21 March 2019) vii <https://www.aihw.gov.au/reports/cancer/cancer-in-australia-2019/formats>.
[27] Cancer Australia, 'Relative Survival by Stage at Diagnosis (Colorectal Cancer)', *National Cancer Control Indicators* (Web Page, 1 April 2019) <https://ncci.canceraustralia.gov.au/outcomes/relative-survival-rate/relative-survival-stage-diagnosis-colorectal-cancer>.
[28] Ibid.

disease are diagnosed as incurable[29] and have a median survival of five to six months with supportive care[30] or 24 months with 'modern systematic regimens'.[31]

2 *Victoria*

To be eligible under the Victorian Act[32], a person's colorectal cancer must be incurable, advanced and progressive, with a prognosis of 6 months or less.[33] The most significant issue in assessing eligibility is prognostication. For example, if the cancer has metastasised to lymph nodes and people in a similar condition have a survival rate of 33%, is the condition incurable? Similarly, it may be difficult to identify an exact timeframe for the disease's progression. Nevertheless, this ambiguity is unlikely to be significant when the criteria are considered collectively. For example, if it is unclear whether or not a person's cancer is curable, death is unlikely to be expected within six months, making the person ineligible regardless.

The clearest cases are Stage IV colorectal cancer. A person's disease at this point is likely to be incurable, advanced and progressive, and their death could be expected within six months without active treatment. As such, advanced metastatic colorectal cancer is clearly capable of satisfying the eligibility criteria. Access to VAD at earlier stages of the disease

[29] Yvette H M Claassen et al, 'Survival Differences with Immediate Versus Delayed Chemotherapy for Asymptomatic Incurable Metastatic Colorectal Cancer' (2018) 11 *Cochrane Database Systematic Review* CD012326:1–33.
[30] Werner Scheithauer et al, 'Randomised Comparison of Combination Chemotherapy Plus Supportive Care with Supportive Care Alone in Patients with Metastatic Colorectal Cancer' (1993) 306(6880) *British Medical Journal* 752.
[31] Alex Grothey et al, 'Survival of Patients With Advanced Colorectal Cancer Improves with the Availability of Fluorouracil-Leucovorin, Irinotecan, and Oxaliplatin in the Course of Treatment (2004) 22(7) *Journal of Clinical Oncology* 1209.
[32] *Victorian Act* (n 14).
[33] Ibid ss 9(1)(d)(i)–(iii).

would depend on the progression of an individual's condition and whether it meets the eligibility criteria.

3 *Western Australia*

Eligibility under the WA Act[34] for colorectal cancer will be similar to the Victorian Act.[35] One key difference is that the WA Act[36] does not require the cancer be incurable. Considered in isolation, the absence of this criterion may broaden access to earlier stages of the disease. However, when viewed holistically with other eligibility criteria – that the condition is advanced and progressive, and expected on the balance of probabilities to cause death within six months – the lack of an incurable criterion is unlikely to make a significant difference in practice.

4 *Model Bill*

Access to VAD under the model Bill[37] will be similar to the Victorian Act,[38] but some people may be able to access VAD earlier in the trajectory of the disease because of the absence of a specified time limit until death. Again, the operation of the criteria holistically is significant. Determinations that the colorectal cancer is incurable, advanced and progressive, and it is expected to cause death, become more important in terms of controlling access in the absence of a required prognosis until death.

Whether or not there is a cure is determined objectively by the doctor; to grant access to VAD, they must be satisfied the disease is incurable and will cause death. A conclusion that

[34] *WA Act* (n 9).
[35] *Victorian Act* (n 14).
[36] *WA Act* (n 9).
[37] Model Bill (n 3).
[38] *Victorian Act* (n 14).

colorectal cancer is incurable will also likely mean it has reached an advanced state, while the presence of metastases or local advancement would indicate the disease is progressive. As with Victoria and Western Australia, patients with Stage IV advanced metastatic cancer will very likely be eligible. However, the absence of a specific time limit until death makes it more likely that access to VAD before Stage IV is also possible (again, provided the above criteria are met).

5 *Oregon*

In Oregon in 2019, 3.2% of VAD deaths were patients with colorectal cancer.[39] Colorectal cancer can meet the requirements to be a terminal disease: that is, incurable and irreversible, and expected (within reasonable medical judgment) to produce death within six months.

6 *Canada*

The Canadian *Criminal Code*[40] allows access to VAD for colorectal cancer[41] at an earlier stage than the other frameworks. Under the *Criminal Code*[42], the cancer must be 'serious and incurable', but incurability appears to be interpreted in practice as the point at which the patient refuses treatment or has tried everything available for a condition that, without treatment, is fatal.[43] The person must also be 'in an advanced state of irreversible decline in capability' and this can be caused by, or be independent of, the serious and incurable

[39] *Oregon Data Summary* (n 10) 10.
[40] Canadian *Criminal Code* (n 6) ss 241.1–241.2.
[41] Note that cancer is the most common underlying condition for individuals who receive VAD in Canada: *Canadian First Annual Report* (n 10) 22.
[42] Canadian *Criminal Code* (n 6) s 241.2(2)(a).
[43] *IRPP Report* (n 17) 16–19. See also White et al, 'Comparative and Critical Analysis of Key Eligibility Criteria for VAD' (n 2) Part II.F.2.a.

disease. So, for example, a very frail elderly person with early stage colorectal cancer refusing all treatment (including surgery at Stage I) may be eligible, while a person who is otherwise healthy and at Stage I would not be eligible (as they are not in an advanced state of irreversible decline in capability).

7 Summary

Cancers are often discussed as the paradigmatic case for access to VAD.[44] It is therefore unsurprising that advanced metastatic colorectal cancer fits within the eligibility criteria in each legislative scheme. While there may be some challenges applying an individual criterion to colorectal cancer, when the criteria are applied holistically, the boundaries of eligibility are relatively clear. Under the Victorian,[45] WA[46] and Oregon[47] Acts, Stage IV colorectal cancer is likely to be eligible, and earlier stages of the disease might also qualify, depending on an individual's circumstances. Earlier access will be more readily available under the model Bill[48], as there is no six months prognosis requirement. The Canadian *Criminal Code*[49] is the most permissive, with access potentially as early as Stage I for people who refuse active treatment and are in an advanced and progressive state of decline due to other comorbid conditions. Several factors underpin this difference in Canada: incurability appears to be based on treatments acceptable to the patient; there is no requirement of temporal proximity until expected death; and a person's state of decline is considered

[44] See, eg, Legal and Social Issues Committee, Parliament of Victoria, *Inquiry Into End of Life Choices* (Final Report, June 2016) 199–202; Ministerial Advisory Panel on Voluntary Assisted Dying, Department of Health and Human Services, Victoria State Government, *Final Report* (Report, 31 July 2017) 12, 78 ('*MAP Report*').
[45] *Victorian Act* (n 14).
[46] *WA Act* (n 9).
[47] *Oregon Act* (n 5).
[48] Model Bill (n 3).
[49] Canadian *Criminal Code* (n 6).

holistically rather than being limited only to that caused by the specific condition (here colorectal cancer).

B *Motor Neurone Disease ('MND')*

1 *Nature of Condition*

MND[50] comprises a rare group of diseases where the nerve cells that control the body's muscles degenerate and subsequently die.[51] It has a prevalence of 8.7 per 100,000 people in Australia.[52] MND causes progressive loss of innervation to muscle groups which leads to weakness, spasticity and wasting.[53] Over time, MND impairs a person's ability to walk, speak, swallow and breathe. The disease is incurable and fatal, but its rate of progression varies significantly depending on the subtype of MND and individual factors. Fifty percent of people with MND live more than three years and around 20% survive between five and ten years from the onset of symptoms.[54] Average life expectancy is two and a half years.[55]

In approximately half of cases, cognition is not affected, but 15% of people have significant impairment with frontotemporal dementia and the remaining 35% experience mild or moderate cognitive impairment, with executive function being most commonly affected.[56]

[50] In North America, this condition is more commonly referred to as amyotrophic lateral sclerosis or 'ALS'. It is also sometimes referred to as Lou Gehrig's disease. This was the relevant condition of a disproportionate number of applicants in court challenges to prohibitions on assisted dying: *Rodriguez v British Columbia (A-G)* [1993] 3 SCR 519; *Carter v Canada (A-G)* [2015] 1 SCR 331 ('*Carter*') (Gloria Taylor); *R* (*Pretty) v DPP* [2002] 1 AC 800; *R (Conway) v Secretary of State for Justice* [2017] EWHC 2447 (Admin); *R (Newby) v Secretary of State for Justice* [2019] EWHC 3118.
[51] 'What is Motor Neuron Disease (MND)?', *MND Australia* (Web Page, 2020) <https://m.mndaust.asn.au/Home.aspx>.
[52] Deloitte Access Economics, *Economic Analysis of Motor Neuron Disease in Australia* (Report, November 2015) 14 ('*Economic Analysis of MND*').
[53] Matthew C Kiernan et al, 'Amyotrophic Lateral Sclerosis' (2011) 377(9769) *Lancet* 942.
[54] Kevin Talbot, 'Motor Neuron Disease: The Bare Essentials' (2009) *Practical Neurology* 9(5) 303.
[55] *Economic Analysis of MND* (n 52) 19, citing Susan T Paulukonis et al, 'Survival and Cause of Death Among a Cohort of Confirmed Amyotrophic Lateral Sclerosis Cases' (2015) 10(7) *PLOS One* e0131965:1–11, 6.
[56] Ringholz GM et al**, '**Prevalence and Patterns of Cognitive Impairment in Sporadic ALS' (2005) *Neurology* 65(4) 586.

2 ***Victoria and Western Australia***

People with MND are likely to qualify for access to VAD in these States at some point in their disease trajectory. MND is an incurable and progressive disease that will cause death. However, the illness would need to have progressed to an advanced stage and the person's prognosis would also need to be that death was expected within 12 months (a longer period applies to a neurological condition).[57] A lack of capacity could preclude access in some cases, given executive function is sometimes impaired, and particularly when a person experiences frontotemporal dementia.

3 ***Model Bill***

People with MND would also be eligible under the model Bill.[58] The key difference from Victoria and Western Australia is the absence of a specified time limit, which means that a person is not required to wait until they are expected to die within 12 months. This potentially provides earlier access to VAD, provided of course that the person's MND is assessed as being advanced. This might also enable access to VAD for people whose MND affects capacity before that capacity is lost.

4 ***Oregon***

In Oregon, MND is the second most common underlying condition for which people receive VAD, after cancer; 10% of all persons who died in 2019 under the Oregon scheme had the disease.[59] Provided a person retains decision-making capacity, MND is a qualifying terminal illness, as it is an incurable and irreversible disease that will produce death. The category of

[57] *Victorian Act* (n 14) s 9(4); *WA Act* (n 9) s 16(1)(c)(ii).
[58] Model Bill (n 3).
[59] *Oregon Data Summary* (n 10) 10–11.

persons who are eligible may be narrower in Oregon than in Victoria and WA, however, as the person must be within six months of death rather than 12 months.

5 *Canada*

A person with MND can be eligible for VAD in Canada.[60] MND meets the serious and incurable disease criterion on diagnosis. A person with MND may therefore be eligible whenever they reach an advanced state of irreversible decline in capability. Given the traditional progression of MND, this decline is unlikely to have occurred at the point of diagnosis, unless the person already had another condition that caused such a decline.

The 'final consent waiver' provision of the Canadian *Criminal Code*[61] allows a person whose natural death is reasonably foreseeable who meets the eligibility criteria, and who is at risk of losing decision-making capacity, to make arrangements to receive VAD after they have lost capacity. To take advantage of the provision, they must make a 'written arrangement' with their provider for VAD to be provided on a specified date. Then, if they lose decision-making capacity, VAD can be provided on or before that date (in accordance with the conditions set out in the written arrangement). It has been stated that in cases of MND, a person's natural death is reasonably foreseeable at the point of diagnosis,[62] so this option of exercising the final consent waiver provision will be available to eligible persons with MND at risk of losing decision-making capacity.

[60] The *Canadian First Annual Report* (n 10) does not provide data specifically on MND but indicates that neurological conditions comprised 10.4% of VAD deaths in the last reporting period: at 22.
[61] Canadian *Criminal Code* (n 6) s 241.2(3.2). See also White et al, 'Comparative and Critical Analysis of Key Eligibility Criteria for VAD' (n 2) Part II.F.1.
[62] The Minister for Health in Parliamentary debates stated that for MND/ALS, a person's death would be reasonably foreseeable at the point of diagnosis 'because it usually happens within a matter of months or years': Canada, *Parliamentary Debates*, Senate, 1 June 2016, 1700 (Jane Philpott). See also Downie and Scallion (n 17) 48–9.

6 *Summary*

A person diagnosed with MND can access VAD under all five frameworks. The key difference is the timing of this access. Oregon has the most restrictive law, requiring a person to be within 6 months of death, followed by Victoria and Western Australia with 12 months. The model Bill[63] does not impose a time limit, but access is constrained by the need for a person's condition to be advanced. This is similar to the position in Canada, but the ability to consider a person's state of decline holistically, not just the decline caused by MND, creates potentially wider access. Canada's final consent waiver provision also permits broader access, ie, when an eligible person has lost decision-making capacity.

C *Chronic Obstructive Pulmonary Disease ('COPD')*

1 *Nature of Condition*

COPD is an incurable and progressive lung disease characterised by chronic airflow limitation, resulting from a mix of emphysema and small airways disease, such as bronchitis.[64] It is the fifth leading cause of death in Australia for both men and women.[65] Increasing airway narrowing and lung destruction causes symptoms to worsen over time. The symptoms include breathlessness, cough and more frequent and persistent chest infections. COPD can progress from Stage I (mild or early-stage) through to Stage IV (often called end-stage COPD), when people may struggle to breathe even at rest. If a person's

[63] Model Bill (n 3).
[64] Global Initiative for Obstructive Lung Disease, *Pocket Guide to COPD Diagnosis, Management and Prevention: A Guide for Health Care Professionals* (Report, 2019) 2.
[65] Australian Government, Australian Institute of Health and Welfare, *Deaths in Australia* (Web Report, 17 July 2019) <https://www.aihw.gov.au/reports/life-expectancy-death/deaths/data>.

respiratory function is so compromised that they lack sufficient oxygen, this may cause confusion and affect a person's decision-making capacity.[66]

People can live for many years with the disease but it does shorten life, particularly when the COPD is advanced.[67] Prognostication is incredibly difficult because the trajectory of COPD is 'chaotic',[68] with slow, chronic decline over time interspersed with acute exacerbations, any of which may cause death.[69]

2 ***Victoria and Western Australia***

COPD is incurable and progressive, and can cause death, particularly when a person has end-stage COPD. A person would need to be at an advanced stage in their illness to be eligible for VAD, particularly given the requirement that death be expected or likely to occur within 6 months. Challenges of prognostication with COPD may present a particular barrier to access.

Decision-making capacity must also be considered as end-stage COPD patients may experience a chronic lack of oxygen in the blood, affecting brain functioning and cognition. This may mean that a person with COPD, despite earlier qualifying for VAD, could lose the required capacity as their illness worsens.

[66] Fiona A H M Cleutjens et al, 'Domain-Specific Cognitive Impairment in Patients with COPD and Control Subjects' (2016) 12 *International Journal of Chronic Obstructive Pulmonary Disease* 1.
[67] Robert M Shavelle et al, 'Life Expectancy and Years of Life Lost in Chronic Obstructive Pulmonary Disease: Findings from the NHANES III Follow-up Study' (2009) 4(1) *International Journal of COPD* 137.
[68] Amanda Landers et al, 'Severe COPD and the Transition to a Palliative Approach' (2017) 13(4) *Breathe* 310, 311.
[69] Ibid.

3 *Model Bill*

A person with COPD could access VAD under the model Bill.[70] Absence of a specified time until death means both that difficulties of prognostication are avoided, and that earlier access may be possible. The person's COPD would still need to be 'advanced', but it would be possible for a doctor to conclude that all eligibility criteria are met at an earlier point than under the Victorian[71] or WA[72] Acts. Therefore, without a requirement to predict timing of death, access to VAD may be provided once a doctor is satisfied that the disease is advanced and will ultimately cause death.

4 *Oregon*

In Oregon, 7.4% of deaths in 2019 listed the underlying illness as 'respiratory [e.g. COPD]'.[73] COPD is 'incurable and irreversible' and so provided the person retained capacity and reasonable medical judgment confirmed death will occur within six months, a person would be eligible for VAD. Uncertainty about disease trajectory could affect the timing of access to VAD.

5 *Canada*

In Canada, 10.8% of VAD deaths in 2018 involved individuals with respiratory conditions.[74] Under the Canadian *Criminal Code*[75], a person with COPD could satisfy the eligibility requirements to access VAD as it is a 'serious' and 'incurable' illness. Because there is no

[70] Model Bill (n 3).
[71] *Victorian Act* (n 14).
[72] *WA Act* (n 9).
[73] *Oregon Data Summary* (n 10) 11.
[74] *Canadian First Annual Report* (n 10) 22.
[75] Canadian *Criminal Code* (n 6) ss 241.2(1), (2).

specified time until death required for a person to be eligible, a person would not have to have reached end-stage. However, because the person must be in an 'advanced state of irreversible decline in capability',[76] a person is unlikely to satisfy this criterion at a very early stage without another comorbid condition causing such decline.

As with MND, because COPD makes a person's natural death reasonably foreseeable, a person with COPD, if they were at risk of loss of capacity, would also be able to access VAD after they lost capacity through the final consent waiver provision.

6 *Summary*

The trajectory to death for COPD patients is unpredictable. A chronically unwell person may live for an extended period of time, experiencing a series of acute events but recovering from them. The different criteria relating to proximity to death in the five frameworks may be practically significant for this condition, with earlier access to VAD in those frameworks which do not specify a requisite time to death. Another key issue is decision-making capacity. If the progression of COPD affects capacity, this may exclude access for those who would otherwise qualify for VAD. As noted above, in Canada, a person may nevertheless be able to access VAD after losing capacity if they have completed a final consent waiver.

D *Chronic Kidney Disease ('CKD')*

1 *Nature of Condition*

CKD involves decreased kidney function (which is determined by the rate at which the kidneys filter wastes from the blood), or markers of kidney damage, or both, for a period of

[76] Ibid s 241.2(2).

at least three months.[77] In most cases, CKD is irreversible, and therefore incurable.[78] In Australia, CKD is estimated to contribute to 11% of all deaths with it being the underlying cause in a quarter of those deaths.[79]

In the early stages of CKD, people may not notice symptoms associated with their reduced kidney function, but as the disease progresses and toxins accumulate, nearly all body systems can be affected. Fluid retention, hypertension, cardiovascular dysfunction and neurological changes are some of the effects of CKD.[80] Patients with CKD are also susceptible to alterations in cognitive function, including stroke and dementia, and this may affect decision-making capacity.[81]

CKD has five stages. Stage I is the least severe, with each stage becoming progressively worse until Stage V, 'end-stage', where the kidneys fail completely.[82] Not all individuals with CKD will progress to end-stage kidney disease and for those that do, the progression is frequently non-linear.[83] This makes prognostication difficult.[84]

2 *Victoria and Western Australia*

[77] Adeera Levin et al, 'KDIGO 2012 Clinical Practice Guideline for the Evaluation and Management of Chronic Kidney Disease' (2013) 3(1) *Kidney International Supplements* 1.
[78] Ibid 19.
[79] Australian Government, Australian Institute of Health and Welfare, *Chronic Kidney Disease* (Web Report, 15 July 2020) <https://www.aihw.gov.au/reports/chronic-kidney-disease/chronic-kidney-disease-compendium/contents/deaths-from-chronic-kidney-disease>.
[80] Carol Mattson Porth and Glenn Maftin, *Pathophysiology: Concepts of Altered Health States* (Lippincott Williams and Wilkins, 8th ed, 2009) 859.
[81] Ria Arnold et al, 'Neurological Complications in Chronic Kidney Disease' (2016) 5 *Journal of the Royal Society of Medicine Cardiovascular Disease* 1.
[82] Andrew S Levey et al, 'Definition and Classification of Chronic Kidney Disease: A Position Statement from Kidney Disease: Improving Global Outcomes (KDIGO)' (2005) 67(6) *Kidney International* 2089, 2094.
[83] National Clinical Guideline Centre (UK), *Chronic Kidney Disease (Partial Update): Early Identification and Management of Chronic Kidney Disease in Adults in Primary and Secondary Care* (NICE Clinical Guidelines No 182, July 2014) ch. 7 <https://www.ncbi.nlm.nih.gov/books/NBK328138/>.
[84] Depending on the person's age and stage of CKD, it can be managed conservatively with diet and observation, by renal replacement therapy with dialysis, or by kidney transplantation: Angela C Webster et al, 'Chronic Kidney Disease' (2017) 389(10075) *Lancet* 1238. The following analysis does not address those circumstances where a person with CKD may be eligible for, or have received, a kidney transplant.

By the later stages of CKD, a person would have a medical condition that is 'advanced and progressive'. There are two challenging aspects under the Victorian[85] and WA[86] Acts, however. First, because the disease's trajectory varies, establishing a six-month prognosis may be difficult. Second, since alterations in cognitive function are possible in the latter stages, if a person loses decision-making capacity for VAD, they will not be eligible.

3 ***Model Bill***

The absence of the prognosis requirement under the model Bill[87] means that earlier access to VAD may be possible than in Victoria or Western Australia. However, the CKD would still need to have reached the stage of being advanced and progressive. Capacity issues remain the same as under the Victorian[88] and WA[89] Acts.

4 Oregon

A very small percentage of Oregonians access VAD on the basis of CKD.[90] CKD satisfies the disease criterion under the Oregon Act, as it is incurable and irreversible and can be a terminal condition. As in Australia, prognosticating about six months until death, and potential loss of capacity present challenges for eligibility.

5 ***Canada***

A person with CKD will meet the serious and incurable condition requirement on diagnosis. However, they must also be in an 'advanced state of irreversible decline'. Barring a

[85] *Victorian Act* (n 14).
[86] *WA Act* (n 9).
[87] Model Bill (n 3).
[88] *Victorian Act* (n 14).
[89] *WA Act* (n 9).
[90] 'Kidney failure' is included in the 'Other illnesses' category, which comprised six individuals (3.2% of VAD deaths) in Oregon in 2019: *Oregon Data Summary* (n 10) 11, 13.

comorbid condition causing such a decline, a person is unlikely to satisfy this criterion at the very early stages of CKD. However, once the CKD and/or the comorbid condition cause the required state of decline, the person may be eligible.

Because the natural death of a person with CKD can be reasonably foreseeable, a person who is at risk of losing capacity after the finding of eligibility will be able to access VAD after they lose capacity through the final consent waiver provision.

6 *Summary*

The uncertain trajectory of CKD and difficulties for prognostication may create challenges for access to VAD in Victoria, Western Australia and Oregon, where death must be expected within six months. This is less of a barrier under the model Bill[91] and in Canada. The potential for cognitive decline associated with CKD may also limit access. In Canada, however, it is possible for a person to exercise the final consent waiver provision and access VAD after they have lost decision-making capacity.

III MEDICAL CONDITIONS FOR WHICH ACCESS TO VAD IS VERY UNLIKELY IN MOST JURISDICTIONS

A *Alzheimer's Disease*

1 *Nature of Condition*

[91] Model Bill (n 3).

Dementia, which refers to a number of neurological conditions where the major symptom is a global decline in brain function,[92] is the second leading cause of death in Australia.[93] Alzheimer's Disease ('Alzheimer's') is the most common form of dementia, affecting up to 70% of people with dementia.[94] Alzheimer's is incurable and its symptoms progressively worsen over time, although the rate at which this occurs varies. Despite this variability, Alzheimer's is usually divided into three broad stages: mild, moderate and advanced.[95] The disease is fatal, usually through complications of the disease, such as swallowing issues or pneumonia. Life expectancy for Alzheimer's varies depending on factors such as whether a person is already of advanced age, but appears to range from three to ten years.[96]

Memory and cognition are specifically affected. For example, persons with moderate Alzheimer's may struggle to remember things that occurred minutes previously. Communication is also affected, both in terms of understanding what is being said and responding.

2 ***Victoria and Western Australia***

[92] The four most common forms of dementia, accounting for over 90% of total cases, are Alzheimer's disease, vascular dementia, frontotemporal dementia and Lewy body disease: Leela R Bolla, Christopher M Filley and Robert M Palmer, 'Dementia DDx: Office Diagnosis of the Four Major Types of Dementia' (2000) 55(1) *Geriatrics* 34.
[93] Australian Bureau of Statistics, *Causes of Death, Australia, 2018* (Catalogue No 3303.0, 25 September 2019).
[94] Kirsten Fiest et al, 'The Prevalence and Incidence of Dementia Due to Alzheimer's Disease: A Systematic Review and Meta-Analysis' (2016) 43(Supp1) *Canadian Journal of Neurological Sciences* S51.
[95] There are also other scales used such as the seven stages in the 'Global Deterioration Scale for Assessment of Primary Degenerative Dementia': Barry Reisberg et al, 'The Global Deterioration Scale for Assessment of Primary Degenerative Dementia' (1982) 139(9) *American Journal of Psychiatry* 1136.
[96] O Zanetti, S B Solerte and F Cantoni, 'Life Expectancy in Alzheimer's Disease (AD)' (2009) 49(Supp 1) *Archive of Gerontology and Geriatrics* 237; Ee Heok Kua et al, 'The Natural History of Dementia' (2014) 14(3) *Psychogeriatrics* 196.

It is very unlikely that a person with Alzheimer's will be eligible to access VAD under the Victorian[97] or WA[98] Acts. Although Alzheimer's is an incurable disease that is progressive and will cause death, it impairs decision-making capacity. By the time a person has reached an advanced state of their disease and is expected to die within 12 months (the longer time limit applies to neurodegenerative conditions),[99] it is very unlikely they would have capacity to make decisions about VAD.[100]

3 *Model Bill*

The position is the same under the model Bill.[101] Even without a time limit until death, it remains very unlikely that a person would retain the requisite decision-making capacity when they have advanced Alzheimer's.

4 *Oregon*

Access to VAD on the basis of Alzheimer's in Oregon is also very unlikely for the same reasons as in Victoria and Western Australia.[102] Indeed, access is even less likely given the shorter time limit of 6 months until death.

5 *Canada*

Alzheimer's qualifies as a serious and incurable condition upon diagnosis so the critical issue is whether a person's Alzheimer's or another comorbid condition is causing them to be in an

[97] *Victorian Act* (n 14).
[98] *WA Act* (n 9).
[99] *Victorian Act* (n 14) s 9(4); *WA Act* (n 9) s 16(1)(c)(ii).
[100] Carmelle Peisah, Linda Sheahan and Ben White, 'Biggest Decision of Them All—Death and Assisted Dying: Capacity Assessments and Undue Influence Screening' (2019) 49(6) *Internal Medicine Journal* 792.
[101] Model Bill (n 3).
[102] This is consistent with the position described here: 'Advance Care Planning for Alzheimer's Disease or Dementia', *Death with Dignity* (Web Page, 2020) <https://www.deathwithdignity.org/alzheimers-dementia-directive/>.

'advanced state of irreversible decline in capability' before they lose decision-making capacity.

There have been a small number of cases in Canada where people with dementia as their sole underlying medical condition accessed VAD.[103] For example, Mary Wilson received VAD after being diagnosed with Alzheimer's at least four years earlier. Her case was referred to the College of Physicians and Surgeons of British Columbia by the coroner, who raised concerns about whether Ms Wilson had a grievous and irremediable medical condition. The College investigated and concluded that Ms Wilson met the eligibility requirements for VAD in the *Canadian Criminal Code,*[104] and the assessing physicians acted reasonably and appropriately when considering the issues of capacity and consent.[105]

Access to VAD for people with dementia before they lose decision-making capacity is also supported in professional guidance given by the Canadian Association of MAiD (Medical Assistance in Dying) Assessors and Providers.[106] The guideline indicates individuals with dementia will be in an advanced state of irreversible decline in capability just prior to when

[103] Kelly Grant, 'From Dementia to Medically Assisted Death: A Canadian Woman's Journey, and the Dilemma of the Doctors Who Helped', *Globe and Mail* (online, 12 October 2019) <https://www.theglobeandmail.com/canada/article-from-dementia-to-medically-assisted-death-a-canadian-womans-journey/>. See also the case of Gayle Garlock: CBC Radio, 'B.C. Man is One of the First Canadians With Dementia to Die With Medical Assistance', *CBC* (online, 27 October 2019) <https://www.cbc.ca/radio/thesundayedition/the-sunday-edition-for-october-27-2019-1.5335017/b-c-man-is-one-of-the-first-canadians-with-dementia-to-die-with-medical-assistance-1.5335025>. These cases occurred when the legislation retained the eligibility requirement of 'natural death' being 'reasonably foreseeable'.
[104] Canadian *Criminal Code* (n 6).
[105] Letter from J G Wilson, Senior Deputy Registrar of the Complaints and Practice Investigations Department of the College of Physicians and Surgeons of British Columbia to Dr Konia Jane Trouton, Dr [redacted] and Dr Paulo Campos Pereira, 6 December 2018 (College File No IC 2018-0034) <https://www.theglobeandmail.com/files/editorial/News/nw-na-maid-1011/marywilson-decision.pdf> ('College Investigation Regarding Death of Mary Wilson').
[106] Canadian Association of MAiD Assessors and Providers, *Medical Assistance in Dying (MAiD) in Dementia* (Clinical Guidance Document, 2019) <https://camapcanada.ca/wp-content/uploads/2019/05/Assessing-MAiD-in-Dementia-FINAL-Formatted.pdf>.

they are likely to lose capacity, so clinicians should assess and monitor a person's capacity and grant access to VAD at this point, also known as the '10 minutes to midnight' approach.

Access to VAD for some people with dementia after they lose decision-making capacity is also possible. If a person with dementia has been found to be eligible for VAD, they can exercise the final consent waiver provision of the Criminal Code and make arrangements for VAD to be provided after they lose decision-making capacity.

6 *Summary*

Access to VAD on the basis of Alzheimer's is very unlikely under the Victorian,[107] WA[108] and Oregon[109] Acts. The requirements to have both decision-making capacity and a condition which is advanced and expected to cause death within a certain time period, will exclude access to VAD. The same result occurs under the Model Bill,[110] despite a lack of timeframe until death being required, as the person with advanced Alzheimer's is similarly very unlikely to have decision-making capacity.

In contrast, under the Canadian law it is possible for a person to retain capacity at the point at which their Alzheimer's causes them to have reached an 'advanced state of irreversible decline in capability'. We consider it significant that the 'advanced' here is in relation to the person's decline and not in relation to the stage of their Alzheimer's. In addition, an individual with Alzheimer's in Canada who is assessed to have capacity and found to meet the eligibility criteria for VAD may exercise the final consent waiver provision and make a written arrangement to have VAD provided after they lose decision-making capacity.

[107] *Victorian Act* (n 14).
[108] *WA Act* (n 9).
[109] *Oregon Act* (n 5).
[110] Model Bill (n 3).

B *Anorexia*

1 *Nature of Condition*

Anorexia nervosa is an eating disorder and serious mental illness. It is a complex condition that combines behavioural disorder, mental disorder and physical illness.[111] Anorexia commonly results in significant physical impairments, including anaemia, osteoporosis and type II diabetes. In severe cases, starvation caused by anorexia can be life-threatening, due to kidney failure, cardiac arrest, suicide, or other complications.[112] Anorexia affects between 0.3% and 1.5% of the Australian population.[113]

While anorexia is not in itself a terminal illness,[114] in some cases, the physical consequences of long-term starvation can become life-threatening. Some describe this as 'end-stage anorexia'[115] or 'terminal psychiatric disease'.[116] Mortality rates vary between 5% and 18%.[117] In some particularly refractory cases of anorexia, treatment has been assessed as

[111] Anorexia involves an intense and obsessive fear of gaining weight, leading to severe food restriction (or purging after eating), often coupled with excessive exercise, resulting in extreme weight loss: Michael J Devlin and Joanna E Steinglass 'Feeding and Eating Disorders' in Janis Cutler (ed), *Psychiatry* (Oxford University Press, 3rd ed, 2014) 2.
[112] National Eating Disorders Collaboration, *Eating Disorders Prevention, Treatment and Management: An Evidence Review* (Report, March 2010) 6 ('*NEDC Report*'); Allan S Kaplan and Blake D Woodside, 'Biological Aspects of Anorexia Nervosa and Bulimia Nervosa' (1987) 55(5) *Journal of Consulting and Clinical Psychology* 645.
[113] James I Hudson et al, 'The Prevalence and Correlates of Eating Disorders in the National Comorbidity Survey Replication' (2007) 61(3) *Biological Psychiatry* 348; *NEDC Report* (n 112) 7.
[114] Around half of patients recover to normal weight and remission of symptoms, a third experience symptom improvement, and only 20% develop chronic anorexia: Hans-Christoph Steinhausen, 'The Outcome of Anorexia Nervosa in the 20th Century' (2002) 159(8) *American Journal Psychiatry* 1284, 1286.
[115] Margery Gans and William B Gunn Jr, 'End stage Anorexia: Criteria for Competence to Refuse Treatment' (2003) 26(6) *International Journal of Law and Psychiatry* 677 ('Gans and Gunn'); Amy T Campbell and Mark P Aulisio, 'The Stigma of "Mental" Illness: End Stage Anorexia and Treatment Refusal' (2012) 45(5) *International Journal of Eating Disorders* 627 ('Campbell and Aulisio').
[116] Joseph O'Neill, Tony Crowther and Gwyneth Sampson, 'Anorexia Nervosa: Palliative Care of Terminal Psychiatric Disease' (1994) 11(6) *American Journal of Hospice and Palliative Medicine* 36.
[117] Ibid; Gans and Gunn (n 115).

futile, and palliative care[118] or VAD[119] has been offered, although both the terminology and the futility of ongoing treatment are disputed.[120]

It remains unresolved whether the physical sequalae of end-stage anorexia are considered to be part of the anorexia or separate, comorbid physical conditions. This is relevant for those VAD frameworks where a specific condition granting access is needed. English and Australian end-of-life cases outside of the VAD context suggest that a person's medical condition should be viewed holistically, and not atomised into separate components of illness, symptoms and consequences.[121]

A further unresolved issue is whether a severely ill anorexic person can have capacity to consent to or refuse medical treatment. Capacity can be compromised by disorders of

[118] Amy Lopez, Joel Yager and Robert E Feinstein, 'Medical Futility and Psychiatry: Palliative Care and Hospice Care as a Last Resort in the Treatment of Refractory Anorexia Nervosa' (2010) 43(4) *International Journal of Eating Disorders* 372. See also the case of Mrs Black, a 45-year old with a 25-year history of anorexia, referred to in Gans and Gunn (n 115) at 678, and the cases of 'Alison' and 'Emily' described in Campbell and Aulisio (n 115) at 628. See also *Re E (Medical Treatment: Anorexia)* [2012] EWCOP 1639 ('*Re E (Medical Treatment: Anorexia)*'); *An NHS Foundation Trust v X* [2014] EWCOP 35 ('*NHS v X*').

[119] In at least two cases from the Netherlands women with anorexia accessed VAD. The first involved a 25-year-old woman who, after 16 years of treatment, weighed 19 kilograms, whose anorexia was considered irremediable, and who was assessed to have competence to request VAD: Barney Sneiderman and Marja Verhoef, 'Patient Autonomy and the Defence of Medical Necessity: Five Dutch Euthanasia Cases' (1996) 34(2) *Alberta Law Review* 374, 393–5. The second involved a woman who suffered from anorexia nervosa, recurrent depression, a personality disorder and a somatoform pain disorder. In later years her anorexia was less significant than her other mental illnesses, and there was no suggestion that she was dying of starvation or its physical effects. She was treated extensively for many years, both in hospital and in the community, including with electroconvulsive therapy, pain medication, and cognitive behavioural therapy, but her condition continued to deteriorate: '2016-01, Psychiatrist, Psychiatric Disorders, No Reasonable Alternative', *Regional Euthanasia Review Committees* (Judgment, 1 January 2016) <https://english.euthanasiecommissie.nl/judgments/d/d-psychiatric-disorders/documents/publications/judgments/2016/2016-01/2016-01> ('Regional Euthanasia Review Committees').

[120] Cynthia Geppert, 'Futility in Chronic Anorexia Nervosa: A Concept Whose Time Has Not Yet Come' (2015) 15(7) *American Journal of Bioethics* 34, 36.

[121] The courts have determined physical illness is part of mental illness in three cases that authorised force feeding of a person who was starving themselves due to mental illness, holding that feeding was 'medical treatment' for symptoms of the person's mental illness: *Adult Guardian v Langham* [2006] 1 Qd R 1; *Australian Capital Territory v JT* [2009] ACTSC 105; *B v Croydon Health Authority* [1995] Fam 133.

values[122] affecting the ability to choose between treatment options, and disorders of executive function affecting rationality of decisions.[123] Starvation also affects cognitive function, including comprehension and reasoning.[124] Some believe that each person with anorexia must be individually assessed to determine whether decision-making capacity is present despite these impairments.[125] However, others consider that people with anorexia *a priori* lack capacity, at least concerning treatment of that condition.[126] There has been at least one reported case in the Netherlands where a young woman with severe anorexia was held to have capacity to choose VAD.[127]

2 *Victoria*

A person with anorexia will ordinarily not be able to access VAD for this condition. This is because the Victorian Act[128] specifically excludes access to VAD based solely on a mental

[122] Louis C Charland, 'Ethical and Conceptual Issues in Eating Disorders' (2013) 26(6) *Current Opinion in Psychiatry* 562; Jacinta A O Tan et al, 'Competence to Make Treatment Decisions in Anorexia Nervosa: Thinking Processes and Values' (2006) 13(4) *Philosophy, Psychiatry, and Psychology* 267.
[123] Geppert (n 120).
[124] Tan et al (n 122) 270.
[125] Sam Boyle, 'How Should the Law Determine Capacity to Refuse Treatment for Anorexia?' (2019) 64 *International Journal of Law and Psychiatry* 250, 257–8; Campbell and Aulisio, (n 115); Heather Draper, 'Anorexia Nervosa and Respecting a Refusal of Life-Prolonging Therapy: A Limited Justification' (2000) 14(2) *Bioethics* 120. Gans and Gunn articulate a series of specific criteria for determining whether an anorexic person has capacity to choose to die: Gans and Gunn (n 115) 693–4.
[126] Christopher J Williams, Lorenzo Pieri and Andrew Sims, 'Does Palliative Care Have a Role in Treatment of Anorexia Nervosa? We Should Strive to Keep Patients Alive' (1998) 317(7152) *British Medical Journal (Clinical Research Edition)* 195, 196; Charland (n 122). In *Re E (Medical Treatment: Anorexia)* (n 118), Peter Jackson J suggested that a person with anorexia can never have capacity to make decisions concerning treatment for that condition: at [51]. Note though in *NHS v X* (n 118), while Ms X was found to lack capacity in relation to decisions about treatment for her anorexia, she was found to have capacity to make decisions about her end-stage liver disease.
[127] Sneiderman and Verhoef (n 119). The second Dutch case mentioned above also involved a woman with anorexia but this condition was no longer as prominent in her overall mental condition by the time she was seeking VAD: Regional Euthanasia Review Committees (n 119). There are also reports of cases where a person with anorexia has been able to access VAD in Canada (eg. Joan Bryden, 'Exclusion of Mental Illness in Assisted Dying-Bill Slammed by Psychiatrists', *CFJC Today* (Web Page, 22 November 2020) <https://cfjctoday.com/2020/11/22/exclusion-of-mental-illness-in-assisted-dying-bill-slammed-by-psychiatrists/>
.
[128] *Victorian Act* (n 14).

illness.[129] Of course, access for a person with anorexia would be possible if they were eligible on the basis of another qualifying medical condition such as cancer or liver failure.[130]

However, there is an argument, drawing on one of the unresolved issues noted above, that anorexia could provide access to VAD. If a person's severe and enduring anorexia has caused substantial and ongoing physical harm (for example, heart disease or kidney failure), then access is not sought for a mental illness but rather for the person's physical condition. A weakness in this argument is that it relies on anorexia being seen as separate from its physical consequences. This is inconsistent with the broad approach that the courts have taken when conceptualising the physical outcomes of a mental illness. It also sits awkwardly with the proposed interpretation of the Victorian Act[131] that a condition may be regarded as causing death if it causes a chain of events that will result in death.[132] Without an authoritative ruling on those issues, it is not possible to be certain about eligibility under the Victorian Act[133] on the basis of anorexia.

In any event, a lack of decision-making capacity is very likely to preclude access. Currently, no English[134] or Australian cases[135] have found a person with severe anorexia to have capacity to make decisions refusing treatment for anorexia.[136] A similar outcome is likely in

[129] Ibid s 9(2). The definition of 'mental illness' in the VAD Act refers to the *Mental Health Act 2014* (Vic) s 4, which defines 'mental illness' as 'a medical condition that is characterised by a significant disturbance of thought, mood, perception or memory.' Anorexia is both a thought disorder and a mood disorder, and would fall within this definition.
[130] For example, in *NHS v X* (n 118), Ms X suffered both severe anorexia (a mental illness) and end-stage liver disease (a physical illness which was caused by her alcohol dependence disorder).
[131] *Victorian Act* (n 14).
[132] See White et al, 'Comparative and Critical Analysis of Key Eligibility Criteria for VAD' (n 2) Part II.B.4.
[133] *Victorian Act* (n 14).
[134] *Re E (Medical Treatment: Anorexia)* (n 118); *NHS Trust v L* [2012] EWCOP 2741; *NHS v X* (n 118); *Re W (Medical Treatment: Anorexia)* [2016] EWCOP 13; *Cheshire & Wirral Partnership NHS Foundation Trust v Z* [2016] EWCOP 56.
[135] *Fletcher (An Infant by her Litigation Guardian Rylands) v Northern Territory* (2017) 324 FLR 11.
[136] However, a person with severe anorexia has been held to have capacity to refuse treatment for comorbid liver disease: *NHS v X* (n 118).

relation to VAD, particularly given that the application of other eligibility criteria mean that this could only arise for severe and enduring cases (see below).

In the highly unlikely event that these hurdles are passed, it is possible that the other eligibility criteria could be met in a small number of cases of severe and enduring anorexia.[137] People suffering the medical sequelae of prolonged starvation may expect death to occur within six months. By this stage, the condition is likely be considered to be advanced and progressive. Further, the person's condition may be considered 'incurable' if all available treatments have not been effective in alleviating the patient's symptoms, or if body systems are failing due to prolonged starvation.

3 *Western Australia*

Applying the above reasoning, there is also a very limited prospect of access to VAD for anorexia under the WA Act.[138] We note, however, that as the condition does not have to be incurable, the possibility of a cure if further treatment is attempted will not be a barrier to accessing VAD.[139]

4 *Model Bill*

While there is a higher likelihood than in Victoria that people with severe and enduring anorexia may be permitted to access VAD under the model Bill,[140] access still remains unlikely given issues of decision-making capacity.

[137] This term is defined as anorexia which is clinically severe, treatment resistant and long lasting: see Anna C Ciao, Erin C Accurso and Stephen A Wonderlich, 'What Do We Know About Severe and Enduring Anorexia Nervosa?' In Steven Touyz, Daniel Le Grange, Hubert Lacey and Phillipa Hay (eds), *Managing Severe and Enduring Anorexia Nervosa: A Clinician's Guide* (Routledge, 2016) 1–12.
[138] *WA Act* (n 9).
[139] Contrast the result in England in the case of *Re E (Medical Treatment: Anorexia)* (n 118).
[140] Model Bill (n 3).

The model Bill[141] has two relevant differences from the Victorian Act.[142] The first is that there is no specific statement precluding access to VAD on the basis of mental illness. This means there is no need to determine whether the person's physical condition is caused by anorexia or can be considered to be separate. In other words, the relevant 'medical condition' may be anorexia with its associated physical complications.

The second major difference is that a specific time until death is not required. The model Bill[143] still requires the condition be incurable and will cause death. The causation condition is assessed on the basis of treatment that is acceptable to the person. This means that access to VAD will be limited to the identified cohort of people with severe and enduring anorexia. However, the absence of a requirement of temporal proximity may enable a person to request VAD at an earlier stage than in Victoria. This earlier assessment for VAD could potentially mean that capacity is less affected by the physical symptoms of starvation which increasingly affect cognition over time.

Despite the above, the requirement that a person retain capacity to make decisions in relation to VAD where it is sought on the basis of anorexia is likely to remain a significant barrier to access.

5 *Oregon*

The phrasing of the mental illness exclusion in the Oregon Act[144] may make it more difficult for a person with severe and enduring anorexia to access VAD. Although not subject to judicial interpretation, the exclusion of a 'psychiatric or psychological condition or

[141] Ibid.
[142] *Victorian Act* (n 14).
[143] Model Bill (n 3).
[144] *Oregon Act* (n 5).

depression impairing judgment' is likely to apply more broadly than a test of decision-making capacity. It would be difficult to maintain that a person with a severe and life-threatening eating disorder, which of its nature centrally affects thoughts and values about eating, did not have some form of impaired judgment, even if this impairment fell short of losing decision-making capacity. The law in Oregon states that a person with such a condition impairing judgment must not be given access to VAD until they are no longer suffering from impaired judgment.[145] This amounts to a categorical exclusion in contrast with the Victorian[146] and WA[147] Acts which still allow access to VAD for person with a mental illness provided they have another qualifying medical condition.

6 *Canada*

Under the Canadian *Criminal Code*, similar to the Victorian[148] and WA[149] Acts, mental illness cannot be considered an 'illness, disease or disability', so a person with anorexia as a sole underlying medical condition is ineligible for VAD. However, on 17 March 2023, the mental illness exclusion will be automatically repealed and so people with anorexia as their sole underlying condition will be potentially eligible for VAD.

A subset of persons with anorexia – those who have 'serious and incurable' comorbid physical conditions as a result of their anorexia – may already be able to meet the criteria of an 'advanced state of irreversible decline in capability' and therefore could qualify for VAD despite the mental illness exclusion.

[145] Ibid § 127.825.
[146] *Victorian Act* (n 14).
[147] *WA Act* (n 9).
[148] *Victorian Act* (n 14).
[149] *WA Act* (n 9).

Access to VAD for some people with anorexia and a comorbid physical condition after loss of decision-making capacity is also possible. If such a person is found to be eligible for VAD, while they have decision-making capacity, they can exercise the final consent waiver provision and make a written arrangement for VAD to be provided after they lose decision-making capacity.

7 Summary

Three of the frameworks (Victoria, Western Australia, and Canada until 2023) aim to specifically preclude people with anorexia from accessing VAD on that basis (because it is a mental illness). However, because anorexia affects eating behaviour, in some extreme cases it can cause physical conditions with life-threatening consequences. Possible access to VAD in Victoria and Western Australia depends on these physical conditions being seen as distinct from the mental illness. This is less of an issue for the model Bill,[150] which does not specifically prohibit access on the basis of mental illness. Under the Canadian *Criminal Code,*[151] a person's decline in capability may be caused by these resulting physical conditions or the anorexia. However, anorexia explicitly does not qualify as a 'serious and incurable illness, disease or disability' and the physical sequelae may not unless they independently amount to an 'illness, disease or disability'.

Access to VAD under all frameworks also depends on the person with severe and enduring anorexia (the application of other eligibility criteria would restrict any potential access to VAD to this cohort) having decision-making capacity. Applying the presumption of capacity, each individual should be carefully assessed to evaluate whether or not their anorexic

[150] Model Bill (n 3).
[151] Canadian *Criminal Code* (n 6) s 241.2(2).

thoughts and values undermine their capacity to choose VAD. However, as discussed above, retaining capacity is likely to be a barrier to accessing VAD for persons with severe and enduring anorexia (except in Canada for a person eligible to exercise the final consent waiver provision in the *Criminal Code*).

C *Frailty*

1 *Nature of Condition*

Frailty is a state of increased vulnerability to adverse health outcomes such as loss of mobility, falls, hospitalisation, disability and death.[152] It reflects the cumulative effects of disease and physiological changes that can occur as people age. It is multidimensional, and clinical manifestations vary widely. Consequently, frailty is generally considered a syndrome rather than a disease.[153] Prevalence is difficult to ascertain[154] but estimates suggest that over 415,000 Australians experience frailty.[155] The physical indicators of frailty have traditionally included reduced activity, slowing of mobility, weight loss, and exhaustion,[156] but more recently the contribution of psychological, social and environmental factors to frailty have been acknowledged.[157] Consistently, longitudinal studies have reported that physical frailty also predicts the onset of future cognitive decline and dementia.[158] Frailty

[152] Andrew Clegg et al, 'Frailty in Elderly People' (2013) 381(9868) *Lancet* 752, 752.
[153] Matteo Cesari et al, 'Frailty: An Emerging Public Health Priority' (2016) 17 *Journal of the American Medical Directors Association* 188, 190.
[154] Shelly Sternberg et al, 'The Identification of Frailty: A Systematic Literature Review' (2011) 59(11) *Journal of the American Geriatrics Society* 2129. Prevalence of frailty ranged from 5% to 58%: at 2131.
[155] D Taylor et al, 'Geospatial Modelling of the Prevalence and Changing Distribution of Frailty in Australia—2011 to 2027' (2019) 123 *Experimental Gerontology* 57.
[156] Linda P Fried et al, 'Frailty in Older Adults: Evidence for a Phenotype' (2001) 56(3) *Journal of Gerontology: Medical Sciences* M146.
[157] R E Pel-Littel et al, 'Frailty: Defining and Measuring of a Concept' (2009) 13(4) *Journal of Nutrition, Health and Aging* 390, 392.
[158] Marco Canevelli, Matteo Cesari and Gabor Abellan van Kan, 'Frailty and Cognitive Decline: How Do They Relate?' (2015) 18(1) *Aging: Biology and Nutrition* 1363.

can progress through a number of stages[159] and is characterised by an inability to recover to baseline function after a minor stressor, such as an infection.[160]

Those who are frail are at increased risk of institutionalisation, morbidity and ultimately mortality, and generally experience a poorer quality of life than those who are not frail.[161] However, without a definitive diagnosis like cancer or heart disease that explains the physical decline, it is often the social, psychological and existential factors that cause the most distress.[162] The absence of a single underlying and diagnosable medical illness or disease means that it is more difficult to demarcate a point of physical decline where death becomes imminent in those who are frail.[163] Consequently, older frail people find themselves in an 'uncertain and dwindling process of dying'.[164]

2 *Victoria, Western Australia, Model Bill and Oregon*

Without a single underlying and diagnosable illness or disease, frailty does not provide a concrete medical condition that will cause death. This is required under the Victorian[165], WA[166] and Oregon[167] Acts, and the model Bill[168], so access to VAD is not possible on the basis of frailty alone under these frameworks.

[159] See, eg, Kenneth Rockwood et al, 2005. 'A Global Clinical Measure of Fitness and Frailty in Elderly People' (2005) *Canadian Medical Association Journal* 173(5): 489–95.
[160] Clegg (n 152).
[161] Pel-Littel et al (n 157) 391.
[162] Anna Lloyd et al, 'Physical, Social, Psychological and Existential Trajectories of Loss and Adaptation Towards the End of Life for Older People Living With Frailty: A Serial Interview Study' (2016) 16(1) *BMC Geriatrics* 176:1–15.
[163] Ibid.
[164] C Nicholson et al, 'Living on the Margin: Understanding the Experience of Living and Dying with Frailty in Old Age' (2012) 75(8) *Social Science and Medicine* 1426, 1427.
[165] *Victorian Act* (n 14).
[166] *WA Act* (n 9).
[167] *Oregon Act* (n 5).
[168] Model Bill (n 3).

3 *Canada*

Individuals can and have received VAD in Canada on the basis of 'complex disease/clinical frailty'.[169] This would involve a determination that a person's frailty constitutes a serious and incurable illness, disease or disability, or that one or more of the person's underlying illnesses, diseases or disabilities contributing to their overall frailty were serious and incurable. To access VAD, the person must also be in an 'advanced state of irreversible decline in capability' which could be caused by a person's frailty or other conditions.

4 *Summary*

Access to VAD for frailty is not possible under the Victorian[170], WA[171] and Oregon[172] Acts, and the model Bill.[173] They require a specified medical condition that will cause death, and frailty does not meet this criterion. By contrast, in Canada, VAD for frailty is possible. Although a serious and incurable illness, disease or disability is required to access VAD, there is no need to demonstrate that it will cause death. Further, in Canada, the advanced state of irreversible decline in capability is assessed globally rather than requiring it to be caused by a particular condition, allowing consideration of a person's frailty holistically.

D *Spinal Cord Injury ('SCI')*

[169] The most recent federal report on VAD in Canada indicates that 6.1% of deaths fall in the category of 'other condition', and notes that 'the category of "other conditions" includes a range of conditions, with frailty commonly cited': *Canadian First Annual Report* (n 10) 22. Data from British Columbia also indicate some VAD deaths in Canada are due to frailty. From 2016–2018 on Vancouver Island, 6.3% of VAD deaths were reported as having 'complex disease/frailty' as the underlying illness: W David Robertson and Rosanne Beuthin, *A Review of Medical Assistance in Dying on Vancouver Island: The First Two Years: July 2016–2018* (Report, November 2018). Likewise, data from VAD assessments in British Columbia indicated four individuals with 'extreme frailty' (and an average age of 92.3 years) had medically-assisted deaths: Ellen Wiebe et al, 'Reasons for Requesting Medical Assistance in Dying' (2018) 64(9) *Canadian Family Physician* 674.
[170] *Victorian Act* (n 14).
[171] *WA Act* (n 9).
[172] *Oregon Act* (n 5).
[173] Model Bill (n 3).

1 *Nature of Condition*

SCI is damage to the spinal cord resulting in loss of mobility or sensation. This encompasses both tetraplegia (previously called quadriplegia) and paraplegia. Tetraplegia is caused by an injury to the upper spinal cord, resulting in some degree of impairment to all four limbs and pelvic organs, and which may affect breathing. Paraplegia is an injury lower down the spinal cord, resulting in loss of function from the chest down, sparing the arms.[174] SCI can affect sensation, control of the limbs and bowel and bladder function. This can be complete or incomplete.[175] SCI may be caused by a single traumatic incident, such as an accident, injury, stroke, or as a complication of medical care or surgery.[176] It may also result from the progression of a degenerative disease such as multiple sclerosis. The following discussion focusses on stable SCI, not degenerative SCI.[177]

The further up the spinal cord the injury occurs, the more serious the symptoms of SCI. Some individuals with tetraplegia require a ventilator to breathe,[178] but many do not. Some require artificial nutrition and hydration, but others are able to ingest food and drink orally.[179] Some are completely paralysed from the neck down, whereas others have partial

[174] Steven C Kirshblum et al, 'International Standards for Neurological Classification of Spinal Cord Injury (Revised 2011)' (2011) 34(6) Journal of Spinal Cord Medicine 535.
[175] This is sometimes referred to as 'complete' or 'incomplete' paralysis, using the American Spinal Injury Association Impairment Scale: Timothy T Roberts, Garrett R Leonard and Daniel J Cepela, 'Classifications in Brief: American Spinal Injury Association (ASIA) Impairment Scale' (2017) 475(5) *Clinical Orthopaedics and Related Research* 1499.
[176] For the causes of SCI in Australia, see Amanda Tovell, Australian Government, Australian Institute of Health and Welfare, *Spinal Cord Injury, Australia, 2014–15* (Injury Research and Statistics Series No 113, Catalogue No INJCAT 202, 16 May 2018) vi, 39 ('*SCI, Australia Statistics*').
[177] Where a person has a progressive SCI due to a degenerative disease such as multiple sclerosis, or a cancerous tumour, eligibility for VAD will be determined by the underlying condition of which the SCI is a symptom.
[178] Rita Galeiras Vázquez et al, 'Respiratory Management in the Patient with Spinal Cord Injury' (2013) BioMed Research International 168757:1–12.
[179] Ginette Thibault-Halman et al, 'Acute Management of Nutritional Demands After Spinal Cord Injury' (2011) 28(8) *Journal of Neurotrauma* 1497.

movement in their arms and hands.[180] Many are wheelchair-bound, but others retain limited mobility.[181]

The prevalence of SCI in Australia is approximately 0.1% of the population.[182] SCIs are generally persisting conditions[183] which are neither progressive nor fatal, but people with SCI have a higher mortality rate and lower life expectancy.[184] They appear to be more susceptible to diseases such as pneumonia, influenza and heart disease.[185]

2 *Victoria and Western Australia*

Under the Victorian[186] and WA[187] Acts, people with SCI will not generally be eligible for VAD, because both statutes specifically state a person is not eligible for VAD only because of disability.[188]

3 *Model Bill*

[180] Christopher S Ahuja et al, 'Traumatic Spinal Cord Injury—Repair and Regeneration' (2017) 80(3 Supp 1) *Neurosurgery* S9.
[181] Jan Mehrholz, Joachim Kugler and Marcus Pohl, 'Locomotor Training for Walking After Spinal Cord Injury' (2012) 11 *Cochrane Database of Systemic Reviews* CD006676:1–42.
[182] World Health Organization, The International Spinal Cord Society and Jerome Bickenbach J (ed), *International Perspectives on Spinal Cord Injury* (Report, 2013) 15–16 ('*International Perspectives on SCI*'). The figure for non-traumatic SCI is based on data from Victoria only, extrapolated to the rest of the country, and includes both children and adults. See generally P J O'Connor, 'Prevalence of Spinal Cord Injury in Australia' (2005) 43 *Spinal Cord* 42.
[183] *SCI, Australia Statistics* (n 176) 2, 4.
[184] Ibid 2.
[185] *International Perspectives on SCI* (n 182) 24–5; J W Middleton et al, 'Life Expectancy After Spinal Cord Injury: A 50-Year Study' (2012) 50 *Spinal Cord* 803; R J Soden et al, 'Causes of Death After Spinal Cord Injury' (2000) 38 *Spinal Cord* 604.
[186] *Victorian Act* (n 14).
[187] *WA Act* (n 9).
[188] *Victorian Act* (n 14) s 9(3); *WA Act* (n 9) s 16(2).

The model Bill,[189] unlike the Victorian[190] and WA[191] Acts, does not specifically exclude people with disability from accessing VAD, but a person with a stable SCI will still be ineligible for VAD. Although their SCI is incurable, it is not progressive.

4 *Oregon*

In Oregon, a person with SCI would not qualify for VAD on that basis as the legislation states no person shall qualify for assistance to die 'solely because of … disability'.[192]

5 *Canada*

Individuals with SCIs as their sole underlying medical condition may be eligible for VAD in Canada, if they are in an 'advanced state of irreversible decline in capability'. Tetraplegia and paraplegia are serious and incurable disabilities. In the Canadian case of *Truchon and Gladu*, two wheelchair-bound individuals with serious and incurable disabilities were held to be eligible to access VAD.[193] However, both plaintiffs in that case had degenerative conditions,[194] not a stable SCI (the focus of this section). It is less clear whether a person satisfies the criterion of 'an advanced state of irreversible decline in capability' where the person has an SCI which involves a significant loss of function but is not progressive or degenerative. Some commentators, such as Downie and Chandler, consider a decline in

[189] Model Bill (n 3).
[190] *Victorian Act* (n 14).
[191] *WA Act* (n 9).
[192] *Oregon Act* (n 5) § 127.805(2).
[193] *Truchon v Canada (A-G)* [2019] QCCS 3792.
[194] Jean Truchon had cerebral palsy coupled with degenerative spinal stenosis and myelomalacia, and Nicole Gladu suffered from degenerative post-polio syndrome.

capability as a result of an SCI which has since stabilised would satisfy this criterion, whereas others consider the decline must be ongoing.[195]

6 *Summary*

A person with SCI will not be eligible for VAD on that basis in Victoria, Western Australia or Oregon because those jurisdictions specifically exclude disability as the sole reason for access to VAD. Under the model Bill[196], a person with a stable SCI will also not be eligible for VAD, because the condition is not progressive. In Canada, however, a person with a stable SCI may be eligible for VAD if the eligibility criteria are interpreted to include a 'decline in capability' which has since stabilised, although the position is not yet resolved.

E *Huntington's Disease*

1 *Nature of Condition*

Huntington's disease ('Huntington's') is a progressive neurodegenerative disease, characterised by constant and uncontrollable jerking motions along with behavioural changes and cognitive decline.[197] This paper considers adult-onset Huntington's, which typically develops between 30 to 50 years of age,[198] however it can manifest at any age

[195] White et al, 'Comparative and Critical Analysis of Key Eligibility Criteria for VAD' (n 2) Part II.F.2.b. Note, however, if a person with an SCI refuses life-sustaining medical treatment (or preventive care where the refusal leads to the need for life-saving medical treatment), this would eventually put them into an advanced state of irreversible decline and would be likely to render them eligible for VAD: see Jocelyn Downie and Matthew Bowes, 'Refusing Care as a Legal Pathway to Medical Assistance in Dying' (2019) 2(2) *Canadian Journal of Bioethics* 73.
[196] Model Bill (n 3).
[197] Sara Parodi and Maria Pennuto, 'Huntington's Disease: From Disease Pathogenesis to Clinical Perspectives' in Kevin Guillory and Alex M Carrasco (eds), *Huntington's Disease: Symptoms, Risk Factors and Prognosis* (Nova Science Publishers, 2013) 1.
[198] National Institute of Neurological Disorders and Stroke, *Huntington's Disease: Hope Through Research* (NIH Publication No 17-NS-19, 31 December 2018) <https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Hope-Through-Research/Huntingtons-Disease-Hope-Through>.

from infancy.[199] If one parent has Huntington's, a child has a 50% chance of developing the condition.[200] It is incurable[201] and death typically occurs around 15 to 25 years after first symptoms, usually from disease complications (such as pneumonia).[202]

Traditionally, five stages of Huntington's are used in research: early, early intermediate, late intermediate, early advanced and advanced.[203] Clinically, three stages—early, middle and late stages—are more often used. It is likely that during the middle to late stages, a person would lose decision-making capacity and lose independence in daily activities.[204]

2 ***Victoria and Western Australia***

Huntington's is an incurable disease (required in Victoria only), which is progressive and will cause death. When a person has a prognosis of 12 months until death, the disease will be in the 'late' stage, so will satisfy the 'advanced' criterion. However, at this point, the person would likely have lost decision-making capacity. As with Alzheimer's disease, these two criteria cannot be fulfilled simultaneously, precluding access to VAD.

3 ***Model Bill***

[199] Francis O Walker, 'Huntington's Disease' (2007) 369(9557) *Lancet* 218.
[200] Ian Freckelton, 'The Legal Ramifications of Huntington's Disease' in Kevin Guillory and Alex M Carrasco (eds), *Huntington's Disease: Symptoms, Risk Factors and Prognosis* (Nova Science Publishers, 2013) 93, 96.
[201] Ibid 98.
[202] Ibid 97.
[203] The Huntington's Disease Functional Capacity Scale was developed by Ira Shoulson: Ira Shoulson, *Clinical Care of the Patient and Family with Huntington's Disease* (Huntington Society of Canada, 1980) 8; Ira Shoulson, 'Huntington Disease: Functional Capacities in Patients Treated with Neuroleptic and Antidepressant Drugs' (1981) 31(10) *Neurology* 1333.
[204] 'How Does Huntington's Disease Progress?', *Huntington's NSW and ACT* (Web Page, 2019) <https://www.huntingtonsnsw.org.au/information/hd-facts/how-does-huntingtons-disease-progress>. See Ian Freckelton, 'Huntington's Disease and the Law' (2010) 18 *Journal of Law and Medicine* 7.

There will be a similar outcome under the model Bill.[205] While the model Bill does not require a prognostic timeframe, the disease must still be 'advanced'. [206] This is likely to be the case only when Huntington's has reached the 'late' stage, at which point a person would have lost decision-making capacity.

4 *Oregon*

A person with Huntington's will not be eligible for VAD in Oregon. The disease is 'incurable and irreversible',[207] but the person will likely not retain capacity at the point when the disease is expected to 'produce death within 6 months'.[208]

5 *Canada*

Huntington's is a 'serious and incurable' disease so eligibility for VAD depends on whether the patient will be in an 'advanced state of irreversible decline in capability'. Particularly if this criterion is assessed by reference to the individual's prior capability rather than an objective standard,[209] a person may reach an advanced state of irreversible *physical* decline relatively early in the disease process. This criterion may therefore be satisfied in the middle stage of Huntington's, rather than the advanced stage. If a person with Huntington's retains decision-making capacity at that point, they will be able to access VAD.

Additionally, if a person wants to access VAD after losing decision-making capacity, they will be able to make arrangements under the final consent waiver provisions for VAD to be

[205] Model Bill (n 3).
[206] Ibid.
[207] *Oregon Act* (n 5) § 127.800(12).
[208] Ibid § 127.805(1).
[209] *IRPP Report* (n 17). See also White et al, 'Comparative and Critical Analysis of Key Eligibility Criteria for VAD' (n 2) Part II.F.2.b.

provided then. This is possible because Huntington's makes a person's natural death reasonably foreseeable (a condition for the exercise of the final consent waiver provision).[210]

6 *Summary*

A person with Huntington's will not be eligible for VAD in Victoria, Western Australia, under the model Bill[211] or in Oregon. The person will likely not have decision-making capacity at the requisite advanced stage of the disease, or when prognostic timelines are satisfied. By contrast, the Canadian *Criminal Code's*[212] framing of the person being in an 'advanced state of irreversible decline of capability', rather than the condition itself being advanced, means access to VAD is possible. The physical symptoms of a person's Huntington's may have reached such a point while the person retains decision-making capacity. Also significant in Canada, given the known trajectory of Huntington's, a person may choose to exercise the final consent waiver provision to access VAD after losing capacity.

IV COMPARATIVE ANALYSIS OF ELIGIBILITY OF DIFFERENT MEDICAL CONDITIONS

This section undertakes a holistic comparative analysis of eligibility for VAD for each of the nine medical conditions across the five legal models. This comparative *practical* analysis (as opposed to the earlier comparative legal analysis[213]) is aided by Table 1 (below). This table cannot comprehensively represent all of the foregoing discussion and so focuses on those aspects critical for possible access to VAD.

[210] See *IRPP Report* (n 17).
[211] Model Bill (n 3).
[212] Canadian *Criminal Code* (n 6).
[213] White et al, 'Comparative and Critical Analysis of Key Eligibility Criteria for VAD' (n 2).

We also mention two other limitations. The first is that this analysis is based on the nine medical conditions examined; other conditions may reveal other issues. The second is that because this is primarily a comparative analysis, it does not provide the basis to reach firm conclusions about what constitutes an optimal VAD model.[214] Differences observed between VAD models do not, without more, indicate which model is better or worse. However, the findings below relating to eligibility will facilitate a further (and deeper) consideration of VAD law and practice. As part of this, some comparisons reveal potentially undesirable outcomes.

[214] Although we note that two of the authors have done this in relation to the model Bill (n 3).

Table 1: Is Access to VAD Possible? Comparative Analysis of Eligibility for Nine Medical Conditions Across Five Legal Frameworks

Condition/ Jurisdiction	Victoria	Western Australia	Model Bill	Oregon	Canada
Medical Conditions for Which Access to VAD is Possible Under All Frameworks					
Colorectal Cancer	Yes, by later stages and once death expected within 6 months	Yes, by later stages and once death expected within 6 months	Yes, by later stages and without curative options	Yes, once death expected within 6 months and without curative options	Yes, once no curative options the person will accept, and person in advanced state of irreversible decline in capability
Motor Neurone Disease ('MND')	Yes, once death expected within 12 months, provided capacity retained	Yes, once death expected within 12 months, provided capacity retained	Yes, once condition is advanced, provided capacity retained	Yes, once death expected within 6 months, provided capacity retained	Yes, once person in advanced state of irreversible decline in capability, provided capacity retained (or final consent waiver)*

Chronic Obstructive Pulmonary Disease ('COPD')	Yes, by later stages, provided capacity retained. Uncertain trajectory may present challenges for death expected within 6 months	Yes, by later stages, provided capacity retained. Uncertain trajectory may present challenges for death expected within 6 months	Yes, by later stages, once condition is advanced and will cause death, provided capacity retained	Yes, by later stages, provided capacity retained. Uncertain trajectory may present challenges for death expected within 6 months	Yes, once person in advanced state of irreversible decline in capability, provided capacity retained (or final consent waiver)*
Chronic Kidney Disease ('CKD')	Yes, by later stages, provided capacity retained. Uncertain trajectory may present challenges for death expected within 6 months	Yes, by later stages, provided capacity retained. Uncertain trajectory may present challenges for death expected within 6 months	Yes, by later stages, provided capacity retained.	Yes, by later stages, provided capacity retained. Uncertain trajectory may present challenges for death expected within 6 months	Yes, once person in advanced state of irreversible decline in capability, provided capacity retained (or final consent waiver)*
*Medical Conditions for Which Access to VAD is Very Unlikely in Most Jurisdictions (**exceptions are in bold**)*					
Alzheimer's Disease	Very unlikely because capacity not retained when death expected within 12 months	Very unlikely because capacity not retained when death expected within 12 months	Very unlikely because capacity not retained when condition becomes advanced	Very unlikely because capacity not retained when death expected within 6 months	**Possible** if person retains decision-making capacity (or final consent waiver)* when in an advanced

					state of irreversible decline in capability
Anorexia	No, because a mental illness. Remote possibility for severe cases on basis of physical sequalae, provided capacity retained	No, because a mental illness. Remote possibility for severe cases on basis of physical sequalae, provided capacity retained	Possible but highly unlikely because capacity in doubt if other eligibility requirements met	No, because a mental illness 'impairing judgment'	**Possible** only if physical sequelae constitute 'a serious and incurable illness, disease or disability', and only if have capacity at that point (or final consent waiver)* Possible even where sole underlying medical condition after 17 March 2023 (when exclusion of mental illness is repealed)
Frailty	No, because no single medical condition will cause death	No, because no single medical condition will cause death	No, because no single medical condition will cause death	No, because no single medical condition will cause death	**Yes**, if person is in advanced state of irreversible decline in capability
Spinal Cord Injury ('SCI')	No, because a disability	No, because a disability	No, because not progressive	No, because a disability	**Probably**, if person interpreted to be in advanced state of

					irreversible decline in capability
Huntington's Disease	No, because capacity not retained when death expected within 12 months	No, because capacity not retained when death expected within 12 months	No, because capacity not retained when condition becomes advanced	No, because capacity not retained when death expected within 6 months	**Yes**, if person retains capacity (or final consent waiver)* when they are in an advanced state of irreversible decline in capability

***** *Where a person's natural death is reasonably foreseeable, a final consent waiver is possible in Canada, provided the person meets the eligibility criteria for VAD . This is noted in Table 1 only in relation to cases where loss of decision-making capacity was discussed in the text.*

A *Access to VAD Shows a Clear Distinction Between the Canadian Model and All Other Models*

Two clear overall conclusions emerge from the comparative practical analysis. The first is that there is a great deal of similarity across the Victorian, Western Australian, model Bill and Oregonian frameworks in terms of access to VAD, despite significant differences in terms of whether a disease must be 'incurable' or whether death must be expected within a particular timeframe. The second is that access to VAD is much broader in Canada.

All five frameworks contemplate VAD for colorectal cancer, MND, COPD and CKD. Access is less straightforward for medical conditions with uncertain trajectories to death such as COPD and CKD, but is nonetheless possible. This is not to say, however, that timing of access to VAD is the same. Generally, access is available latest in Oregon (always six months) and in Victoria and Western Australia (generally six months but 12 months for neurodegenerative conditions). The model Bill[215] provides earlier access for these medical conditions as the Bill does not stipulate that death must be anticipated within a specified time limit, and indeed this helps avoid some issues with predicting timing of death for conditions with uncertain trajectories. The Canadian framework provides the earliest access to VAD for these conditions: whenever a person has reached an 'advanced state of irreversible decline in capability', which is interpreted broadly.

Our analysis demonstrates that the other medical conditions considered (Alzheimer's, anorexia, frailty, SCI and Huntington's) are generally precluded from VAD under eligibility

[215] Ibid.

criteria in the Victorian[216], WA[217] and Oregon[218] Acts, and the model Bill.[219] But the position is different under Canadian law where access is possible (and sometimes probable) for all of these medical conditions. The eligibility criteria in the Canadian *Criminal Code*[220] are broader, due to three (interrelated) factors.

The first is that access to VAD does not depend on proximity or likelihood of death. The second is that to establish a 'grievous and irremediable medical condition', the Canadian criteria do not require a causal connection between the 'serious and incurable illness, disease or disability' and the 'advanced state of irreversible decline in capability'. By contrast, the other frameworks require that the condition *cause* the relevant outcome (death in those models). The third factor is that the requirement that a person's condition is 'advanced' is framed differently: Canadian law requires an advanced decline in *capability of the person*, whereas other models assess whether the person's *medical condition* itself has reached an advanced state. These last two features mean that a person's advanced state of irreversible decline in capability can be assessed globally, taking into account their entire health status and all possible medical conditions (not just the qualifying condition).

B *Impact of Time Limits Until Death on Access to VAD*

Eligibility criteria address not only the question of *whether* VAD can be accessed, but *when*. This comparative practical analysis demonstrates the impact of including an eligibility requirement that a person be expected to die within a specified time period. This is best

[216] *Victorian Act* (n 14).
[217] *WA Act* (n 9).
[218] *Oregon Act* (n 5).
[219] Model Bill (n 3).
[220] Canadian *Criminal Code* (n 6) s 241.2(1).

illustrated by comparing access to VAD under the Victorian Act[221] (a time limit of six and sometimes 12 months until death) with the model Bill[222] (very similar eligibility criteria, but no time limit, requiring only that the condition cause death). For eight of the nine conditions considered in this paper, potential eligibility under the model Bill[223] was the same as in Victoria.[224] The sole possible exception was for anorexia, which possibly could be eligible under the model Bill[225] (although highly unlikely) since it does not specifically exclude mental illness. In other words, the six or 12-month time limit until death in Victoria had no impact on restricting the medical conditions that would permit access to VAD when compared with the model Bill.[226] This is because the model Bill's requirement for a person's medical condition to be 'advanced' constrains access to similar cases.[227]

This raises questions about the utility of requiring a time until death in VAD eligibility criteria. If the purpose is to exclude access to VAD for certain medical conditions, then it does not appear to be necessary, at least in relation to these medical conditions. However, if the purpose is to reserve VAD only for those who are at the end of their lives,[228] it is effective. One of the conclusions of this comparative analysis is that the time limits in the

[221] *Victorian Act* (n 14).
[222] Model Bill (n 3).
[223] Ibid.
[224] This same result also applies in relation to the *WA Act* (n 9) and *Oregon Act* (n 5). The rationale for the specific comparison between the *Victorian Act* (n 14) and the model Bill (n 3) is the relevant wording of the eligibility criteria in the two frameworks is almost identical but for the imposition of a time limit until death in Victoria.
[225] Model Bill (n 3).
[226] Ibid.
[227] Ibid.
[228] Indeed, the intention of the *Victorian Act* (n 14) was that VAD would only be available for those people who are 'close to death' and at the 'end of life': *MAP Report* (n 44) 13–14.

Victorian,[229] WA[230] and Oregon[231] Acts restrict access to a later stage in a person's medical condition than under the model Bill.[232]

Such a time-based approach has a number of undesirable outcomes. One examined above is the difficulty a time limit can cause for prognostication, particularly for medical conditions with an unpredictable trajectory to death. This can mean that a person whose condition will cause death may not be eligible because the nature of their illness does not provide a reliable guide to how far away their death may be. Another undesirable outcome is the additional suffering that a person, who is otherwise eligible for VAD, must endure while waiting to fall within the prescribed proximity to death.[233] Further, this approach also risks preventing otherwise eligible people from accessing VAD, if the delay until death is approaching means that they are not well enough to navigate the assessment process. We consider that jurisdictions contemplating reform should reflect on these undesirable outcomes and whether a specified time limit until death is justifiable.

C *Impact of Decision-Making Capacity on Medical Conditions That Will Permit Access to VAD*

All five frameworks require a person has decision-making capacity to access VAD. Capacity issues specifically arose in six of the nine conditions considered: MND, COPD, CKD, Alzheimer's, anorexia and Huntington's.[234] The progression of some conditions can have a

[229] *Victorian Act* (n 14).
[230] *WA Act* (n 9).
[231] *Oregon Act* (n 5).
[232] Model Bill (n 3).
[233] Ben P White et al, 'Does the Voluntary Assisted Dying Act 2017 (Vic) Reflect its Stated Policy Goals?' (2020) 43(2) *University of New South Wales Law Journal* 417, 433 ('Does the VAD Act Reflect its Stated Policy Goals?').
[234] Of course, even for conditions which do not of themselves specifically impair capacity, the progression of those conditions or side effects can raise capacity issues, for example pain and symptom management can require taking medication that can impair capacity.

consequential impact on decision-making capacity. For example, COPD can cause a lack of oxygen to the brain. For other conditions, such as Alzheimer's and Huntington's, a lack of decision-making capacity is a defining feature of the condition and a key reason why VAD is generally not permitted for these conditions (except in Canada).

This demonstrates the significant implications that decision-making capacity has for access to VAD. Advance directives or requests for VAD have been proposed as a mechanism to address these issues, but there have been challenges with the uptake and useability of such tools in jurisdictions where they are lawful and for which there are data.[235] Nevertheless, community desire remains high for mechanisms to support access to VAD for conditions such as Alzheimer's after a loss of capacity.[236] This has led to some jurisdictions specifically identifying this issue as warranting further consideration.[237] We support this, and

[235] Research also suggests advance directives or requests for VAD are often not followed in practice: Marike E de Boer et al, 'Advance Directives for Euthanasia in Dementia: Do Law-Based Opportunities Lead to More Euthanasia?' (2010) 98(2) *Health Policy* 256; Mette L Rurup et al, 'Physicians' Experiences with Demented Patients with Advance Euthanasia Directives in the Netherlands' (2005) 53(7) *Journal of the American Geriatrics Society* 1138. Use of these directives remains controversial: Paul Mevis et al, 'Advance Directives Requesting Euthanasia in the Netherlands: Do They Enable Euthanasia for Patients Who Lack Mental Capacity?'(2016) 4(2) *Journal of Medical Law and Ethics* 127; Karin R Jongsma, Marijke C Kars and Johannes J M van Delden, 'Dementia and Advance Directives: Some Empirical and Normative Concerns' (2019) 45(2) *Journal of Medical Ethics* 92; David Gibbes Miller, Rebecca Dresser and Scott Y H Kim, 'Advance Euthanasia Directives: A Controversial Case and its Ethical Implications' (2019) 45(2) *Journal of Medical Ethics* 84. There is not yet any data in Canada for advance requests made through 'final consent – waiver' or 'advance consent – self administration' (under s 241.2(3.5) of the Canadian *Criminal Code* (n 6)).

[236] People with Alzheimer's desire to have access to assisted dying, including via advance directives: Alzheimer's Australia Victoria, *A Good Death is My Right* (Discussion Paper, April 2017) 9–10; Dementia Australia, *Submission to the Ministerial Expert Panel on Voluntary Assisted Dying* (Discussion Paper, May 2019) 7; *Queensland Parliamentary Report* (n 4) 123–5.

[237] In Canada, the Minister of Justice and the Minister of Health were required to initiate an independent review into advance requests for VAD within six months of the initial legislation passing: Bill C-14 (n 6) s 9(1). The result was the following report: Council of Canadian Academies, *The State of Knowledge on Advance Requests for Medical Assistance in Dying: The Expert Panel Working Group on Advance Requests for MAiD* (Report, 12 December 2018). This issue will again be considered during a Parliamentary review in response to Bill C-7: Government of Canada, Department of Justice 'Canada's New Medical Assistance in Dying Law' (webpage, 19 March 2021) <https://www.justice.gc.ca/eng/cj-jp/ad-am/bk-di.html>. In Queensland, the parliamentary committee inquiring into VAD recommended further research into the issue of advance requests for VAD by persons with dementia: *Queensland Parliamentary Report* (n 4) 127 'Recommendation 7'. See also the 'Statement of Reservation' of Michael Berkman MP, supporting further research into this issue: at 197–8.

recommend jurisdictions contemplating reform actively investigate how this complex policy issue could be addressed. Some recognition of the desire for VAD after loss of capacity is found in Canada through the final consent waiver. The '10 minutes to midnight' approach for assessing capacity of individuals with dementia has been another Canadian response to this issue (although it maintains the requirement that a person has capacity immediately prior to the provision of VAD).

D *Impact of Excluding Types of Medical Conditions From Access to VAD*

A legislative drafting device employed in some VAD frameworks is excluding particular categories of conditions from access to VAD. The two excluded conditions in these frameworks are disability (Victoria, Western Australia and Oregon)[238] and mental illness (all frameworks except the model Bill).[239] One limitation of this analysis is that only one type of mental illness (anorexia) and one disability (SCI) were considered. More robust testing is needed in relation to a range of mental illnesses and disabilities but this comparative analysis does identify some important questions.

Excluding disability as a ground for VAD under some statutes did not create different outcomes between those laws and the model Bill[240] for stable SCI. In relation to anorexia, however, there may be a different outcome. Under the model Bill,[241] access to VAD, though highly unlikely, may be possible for a small cohort of persons with severe and enduring anorexia whose illness is objectively considered to be incurable, is advanced and progressive and likely to cause death. (However, the person, despite the severity of their condition,

[238] *Victorian Act* (n 14) s 9(3); *WA Act* (n 9) s 16(2); *Oregon Act* (n 5) § 127.805(2).
[239] *Victorian Act* (n 14) s 9(2); *WA Act* (n 9) s 16(2); *Oregon Act* (n 5) § 127.825. The exclusion of access to VAD on the basis of mental illness in Canada is proposed in Bill C-7 (n 6) cl 1(2), proposed s 241.2(2.1).
[240] Model Bill (n 3).
[241] Ibid.

must retain capacity to seek VAD and this is highly unlikely.) Although these criteria are identical in the Victorian Act,[242] and very similar in the WA Act,[243] the specific exclusion of mental illness in those jurisdictions likely precludes access to VAD, assuming that the physical sequelae of the illness are not considered a separate terminal condition providing access.

As mentioned, more analysis is needed to assess access to VAD for a range of mental illnesses. We note that anorexia is atypical of mental illnesses, in that it can result in life-threatening physical conditions which can be fatal. But this analysis invites the question whether a blanket exclusion from access to VAD based on mental illness is justifiable when the eligibility criteria are otherwise met.[244]

V IMPLICATIONS OF ANALYSIS OF MEDICAL CONDITIONS FOR DESIGN OF VAD REGULATION

The comparative legal analysis in the first paper[245] in this two-part series identified important implications for designing VAD regulation. This section extends that work and

[242] *Victorian Act* (n 14).
[243] *WA Act* (n 9).
[244] Udo Schuklenk and Suzanne van de Vathorst, 'Treatment-Resistant Major Depressive Disorder and Assisted Dying' (2015) 41(8) *Journal of Medical Ethics* 577; Justine Dembo, Udo Schuklenk and Jonathan Reggler, '"For Their Own Good": A Response to Popular Arguments Against Permitting Medical Assistance in Dying (MAiD) where Mental Illness Is the Sole Underlying Condition' (2018) 63(7) *Canadian Journal of Psychiatry* 451; Isra Black, 'Suicide Assistance for Mentally Disordered Individuals in Switzerland and the State's Positive Obligation to Facilitate Dignified Suicide' (2012) 20(1) *Medical Law Review* 157, 164–5. Note also the Canadian Council of Academies work on mental illness as sole underlying medical condition to access VAD: Council of Canadian Academies, *The State of Knowledge on Medical Assistance in Dying Where a Mental Disorder is the Sole Underlying Medical Condition: The Expert Panel Working Group on MAiD Where a Mental Disorder is the Sole Underlying Medical Condition* (Report, 12 December 2018). The Canadian government will commission an independent expert review into the requisite protocols, guidance and safeguards to apply to VAD requests based on mental illness as a sole underlying condition, with recommendations due by 17 March 2022: Bill C-7 (n 6) s 3.1.
[245] White et al, 'Comparative and Critical Analysis of Key Eligibility Criteria for VAD' (n 2).

focuses on what the comparative *practical* analysis of access to VAD for different medical conditions reveals about design of VAD regulation.

A *Test Eligibility Criteria in Relation to Medical Conditions to Ensure Criteria Operate as Intended*

The purpose of eligibility criteria is to determine who will and will not be permitted to access VAD. Careful testing of these criteria by reference to a wide range of medical conditions prior to legislating enables policy-makers to determine if the proposed criteria will operate in practice as intended. As the analysis presented here demonstrates, it also highlights whether when criteria are applied holistically (see below), there are some criteria that may be redundant. An example might be a specified time until death (as discussed above), depending on policy-makers' intent. Evaluating which medical conditions could facilitate access to VAD should also continue *after* a VAD law is passed. Such a review requires robust data collection including about who is accessing VAD and on the basis of which medical conditions. Such data should also include who is being refused access to VAD and the role (if any) of individuals' medical conditions in those decisions.

B *Eligibility Criteria Operate Holistically*

As observed in the preceding paper, eligibility criteria in VAD frameworks are intended to operate holistically.[246] This was clear on the face of the legislation and from the comparative legal analysis, but became particularly apparent when these criteria were applied to the nine medical conditions. An illustration of this is that differently formulated eligibility

[246] Ibid Part IV.C.

criteria can achieve the same result in terms of which medical conditions permit access to VAD.

For example, in Victoria and under the model Bill,[247] a person's condition must be 'incurable', but this is not required in Western Australia. In Victoria and Western Australia, doctors must prognosticate about time until death, but this is not required in the model Bill.[248] Yet across these three frameworks, applying the criteria holistically, the same medical conditions provided access to VAD (save perhaps a possible difference in the exceptional case of anorexia). This is because the absence of one aspect of the criteria in a particular framework was compensated for by the collective operation of the other components. This should alert policymakers to consider whether each individual criterion is required, or whether a particular criterion may be redundant given the presence of other, determinative, factors.

A holistic application of eligibility criteria means not only applying all criteria concurrently but also considering causal relationships between them. Systematically applying five frameworks to nine selected medical conditions revealed how causal relationships between criteria (or their absence) have a significant impact on access to VAD. All frameworks except Canada require a causal relationship between the person's medical condition and expected death, which narrows eligibility. In contrast, the Canadian model does not require a causal link between the 'serious and incurable condition' and the 'advanced state of irreversible decline' a person experiences. As a result of this (and other factors), access to VAD in Canada is broader than under the other frameworks.

[247] Model Bill (n 3).
[248] Ibid.

C *Challenge of Translating Policy Goals into Legislation*

The challenges of designing VAD legislation that reflects its desired policy goals and is capable of being consistently interpreted and applied as intended were noted earlier in the comparative legal analysis.[249] These challenges were further illuminated by applying the five frameworks to the nine medical conditions. In relation to reflecting policy goals, crafting eligibility criteria that are not either over-inclusive or under-inclusive when compared with the objectives underpinning the law presents a specific challenge for rule design.[250] In other words, there is a risk that individuals whom the policy intent was to permit to access VAD are excluded by the legislation, or a risk that those whom the intent was to exclude from VAD can obtain access.

This was demonstrated in the comparative practical analysis where mental illness is specifically excluded as a basis for VAD. To some extent, this is an attempt to create a clear rule and certainty in relation to eligibility (putting aside definitional questions such as what constitutes a mental illness and how to characterise any physical sequelae). By preferencing certainty through directly excluding a category of cases, the difficulty of determining whether a person with a mental illness could otherwise qualify for VAD is avoided. But this may not be consistent with the law's overall policy goals as reflected in the generic eligibility criteria (or at least reflects inconsistency within those goals) and risks under-inclusion.

[249] White et al, 'Comparative and Critical Analysis of Key Eligibility Criteria for VAD' (n 2) Part IV.A; Karen Yeung, 'Regulating Assisted Dying' (2012) 23(2) *King's Law Journal* 163.
[250] Yeung (n 249) 168. A discussion of the policy goals underpinning these frameworks is beyond the scope of this paper. The principles guiding the Victorian VAD law are contained in *MAP Report* (n 44) 43–6 and evaluated in White et al, 'Does the VAD Act Reflect its Stated Policy Goals?' (n 233). In relation to Western Australia, see Ministerial Expert Panel on Voluntary Assisted Dying, Department of Health, Government of Western Australia, *Final Report* (Report, 4 June 2019) ('*MEP Report*'). The values underpinning the Model Bill are set out in model Bill (n 3); Lindy Willmott and Ben White, 'Assisted Dying in Australia: A Values-Based Model For Reform' in Ian Freckelton and Kerry Petersen (eds), *Tensions and Traumas in Health Law* (Federation Press, 2017) 479. The Canadian law is based on *Charter* rights as identified in *Carter* (n 50).

This is illustrated in Victoria where the Ministerial Advisory Panel, whose recommendations unpinned the Act,[251] supported a blanket exclusion of access to VAD on the basis of mental illness 'because it is not a medical condition that "will cause death"'[252] and, therefore, could not satisfy the eligibility criteria. However, this is inconsistent with the analysis above in relation to at least one mental illness: anorexia, which is capable of causing death in severe cases. If the Panel was intending only to use the blanket exclusion as a clear means of confirming the operation of the eligibility criteria, then this may not be intended result. Further, the Panel's stated policy intent was: 'To ensure people with mental illness are afforded the same rights and protections as other members of the community and that people with mental illness who meet all of the eligibility criteria are not unreasonably denied access to voluntary assisted dying.'[253] The explicit exclusion of mental illness may be inconsistent with this stated policy intent. If the intention was to exclude mental illness because such conditions were considered an inappropriate basis to access VAD, then this additional exclusion warrants express justification at a policy level.

The other major regulatory challenge in relation to the five VAD frameworks relates to rule indeterminacy and interpretation.[254] In the process of applying the various eligibility criteria to nine medical conditions, it became clear that how and when some criteria were met for particular conditions was not straightforward. Examples include when does a medical condition become 'advanced' and 'progressive', and what constitutes an 'advanced state of irreversible decline in capability'. But even requirements such as an expected time until death, which can ostensibly appear more concrete and certain, have been shown to be

[251] *Victorian Act* (n 14).
[252] *MAP Report* (n 44) 81.
[253] Ibid 82.
[254] Yeung (n 249) 168–9.

unclear and difficult to apply in practice in some situations. Indeed, challenges of prognostication could mean that determining likely time until death is more uncertain than other eligibility criteria, such as for particular conditions that have strong clinical criteria for determining when they become 'advanced' and 'progressive'.

This breadth in interpreting the criteria could be seen as positive because this permits some flexibility for doctors to apply them to individual patients in a meaningful way. However, this ambiguity may lead to doctors (and regulators) applying these concepts inconsistently in practice. This is a known challenge not only in designing VAD laws but in regulation more generally.[255] Another concern is that where there is uncertainty, eligibility criteria may be applied conservatively to avoid possible liability. A response to these concerns is to provide other support to guide consistent application of the criteria in practice that aligns with the framework's intent.

D *Developing Guidance and Support to Interpret VAD Frameworks*

Consistent interpretation of VAD frameworks to advance the intended policy goals is desirable. The comparative analysis of the medical conditions revealed how, particularly for conditions for which eligibility may be difficult to assess, it may be desirable to develop guidance about implementation of VAD frameworks in practice. From a legal perspective, clarification of legislation often occurs via case law and this has occurred in Canada during the relatively short period that VAD has been in operation.[256] However, this may not occur;

[255] Ibid 168–70; Lutz-Christian Wolff, 'Law and Flexibility—Rule of Law Limits of a Rhetorical Silver Bullet' (2011) *Jurisprudence* 549.

[256] Judicial interpretation of the Canadian legislative criteria has occurred in one case *AB v Canada (Attorney General*) [2017] ONSC 3759 (meaning of 'natural death has become reasonably foreseeable'). In Victoria, the Victorian Civil and Administrative Tribunal has interpreted the meaning of the 'residence' criterion in the Victorian Act: *NTJ v NTJ (Human Rights)* [2020] VCAT 547. We also note that clarification of legislation can also occur by amending the legislation itself.

we are not aware of any cases interpreting Oregon's law, despite being operational for over 20 years. Further, courts can only address issues raised by the parties' factual situation, not every situation where interpretive clarification is needed. Reliance on judicial clarification is also problematic as by definition the individuals concerned are seriously ill and suffering, and may not be able or have time to pursue legal challenges through courts.

Accordingly, other tools of regulation are needed to guide decision-making under the VAD frameworks. In Canada, guidelines and policies have been produced by medical regulators and the Canadian Association of MAiD Assessors and Providers.[257] Decisions by regulators in particular cases, if made public by the regulator or the clinician investigated, may also contribute to interpretation of statutory provisions.[258] And one of the authors, academic Jocelyn Downie, has worked with colleagues to clarify key terms in the Canadian *Criminal Code.*[259] This has occurred in a variety of ways including through a policy roundtable process which produced a report with recommended interpretations.[260]

[257] For example, Canadian Association of MAiD Assessors and Providers, *The Clinical Interpretation of 'Reasonably Foreseeable'* (Clinical Practice Guideline, June 2017); Canadian Association of MAiD Assessors and Providers, *Assessment for Capacity to Give Informed Consent for Medical Assistance in Dying (MAiD) Review and Recommendations* (White Paper, April 2020); Canadian Association of MAiD Assessors and Providers, *Medical Assistance in Dying (MAiD) in Dementia* (Clinical Guideline, May 2019); 'Professional Standard Regarding Medical Assistance in Dying (MAiD)', College of Physicians and Surgeons of Nova Scotia (Web Page, May 8, 2021) <https://cpsns.ns.ca/resource/medical-assistance-in-dying/>. Policies of other medical colleges are available at the End of Life Law and Policy in Canada webpage: Health Law Institute, Dalhousie University, 'Clinical Guidance Documents', *End of Life Law and Policy in Canada* (Web Page, 2020) <http://eol.law.dal.ca/?page_id=2657>.

[258] Two regulator decisions that have been made publicly available are those in relation to Mary Wilson (discussed above) and Ms S: see College Investigation Regarding Death of Mary Wilson (n 105); Complaints and Practice Investigations Department, College of Physicians and Surgeons of British Columbia, 'Final Disposition Report of the Inquiry Committee' (Report, CPS File No IC 2017-9836, 13 February 2018) <http://eol.law.dal.ca/wp-content/uploads/2017/11/College-letter-.pdf>. In relation to the latter decision, see: Jocelyn Downie, 'Has Stopping Eating and Drinking Become a Path to Assisted Dying', Policy Options (online, 23 March 2018) <https://policyoptions.irpp.org/magazines/march-2018/has-stopping-eating-and-drinking-become-a-path-to-assisted-dying/>.

[259] Canadian *Criminal Code* (n 6).

[260] *IRPP Report* (n 17). Downie has also written a series of academic papers analysing and interpreting various aspects of the legislation: Downie and Scallion (n 17); Jocelyn Downie and Justine Dembo, 'Medical Assistance

Regulatory bodies with responsibility for VAD oversight can also help guide behaviour. For example, in the Netherlands, the Regional Euthanasia Review Committees publish detailed summaries of VAD cases.[261] These summaries are also indexed in terms of various domains, most importantly for present purposes into straightforward cases and non-straightforward cases, as well as those cases where the 'due care criteria' were complied with and those where it was not. This publicly available guidance can help to promote consistent interpretation of the law. A VAD oversight body may also be able to provide prospective guidance in particular cases or on particular topics. For example, the remit of such a body could include providing advice on a complex case about which a doctor wanted reassurance, or issue an opinion about a category of case, such as VAD for anorexia given the unresolved issues raised above.

The Canadian and other work described above has, however, been primarily reactive in that it occurred after the law had passed. It is also possible, and desirable, to utilise wider tools of regulation to promote consistent understanding and application of eligibility criteria before the law commences. One example in Australian models is the mandatory training doctors must undertake prior to assessing a patient's eligibility for VAD.[262] This establishes a minimum baseline understanding of the legislative framework and provides guidance on how it should be interpreted.[263]

in Dying and Mental Illness Under the New Canadian Law' (2016) *Journal of Ethics in Mental Health* 1; Downie and Bowes (n 195); Gus Grant and Jocelyn Downie, 'Time to Clarify Canada's Medical Assistance in Dying Law' (2018) 64(9) *Canadian Family Physician* 641.

[261] 'Judgments', *Regional Euthanasia Review Committees* (Web Page, 2018) <https://english.euthanasiecommissie.nl/judgments/>.

[262] *Victorian Act* (n 14) ss 17, 26; *WA Act* (n 9) ss 25, 36; model Bill (n 3) cl 14.

[263] Ben P White et al, 'Development of Voluntary Assisted Dying Training in Victoria, Australia: A Model for Consideration' (2020) *Journal of Palliative Care* (early online, https://doi.org/10.1177/0825859720946897). Guidance for health practitioners is also provided in other forms: see, eg, Victorian Department of Health and Human Services, Victoria State Government, *Voluntary Assisted Dying: Guidance for Health Practitioners* (Clinical Guideline, 4 July 2019).

VI CONCLUSION

In this paper and its companion paper, we have undertaken comparative legal and practical analyses of five VAD frameworks in relation to nine medical conditions. This has generated new insights into these legal models and implications of their design in practice. We acknowledge that the comparative methodology does not permit strong normative conclusions about an optimal VAD framework; different does not necessarily mean better or worse.[264] That said, these analyses have revealed significant undesirable outcomes in some aspects of these frameworks, highlighted doubts about their effectiveness in achieving stated policy goals, and identified important considerations for policy-makers contemplating VAD reform.

VAD reform in further states is being actively considered in Australia.[265] Other countries are also contemplating reform, including the United Kingdom,[266] parts of Europe[267] and other states in the United States.[268] These papers have implications for those reform exercises. In

[264] John C Reitz, 'How to Do Comparative Law' (1998) 46(4) *The American Journal of Comparative Law* 617, 624–5.

[265] After this article was submitted for publication, Tasmania passed the *End-of-Life-Choices (Voluntary Assisted Dying) Act 2021*. South Australia and Queensland have a Bill before parliament: the Voluntary Assisted Dying Bill 2020 (SA) and the Voluntary Assisted Dying Bill 2021 (Qld), respectively. In NSW, a VAD Bill is proposed to be introduced at some point in 2021: Michael Koziol, 'Fresh bid to legalise assisted dying set to test NSW government', *Sydney Morning Herald* (online, 13 December 2020) <https://www.smh.com.au/politics/nsw/fresh-bid-to-legalise-assisted-dying-set-to-test-nsw-government-20201209-p56m2t.html>.

[266] See, eg, the discussion of legislative and judicial developments in the United Kingdom in relation to VAD in *R (Conway) v Secretary of State for Justice* [2018] EWCA Civ 1431, [18]–[48].

[267] For example, in Portugal, five bills aimed at decriminalising VAD have been introduced: 'Portugal MPs in Move to Legalise Euthanasia', *BBC News*, (online, 21 February 2020) <https://www.bbc.com/news/world-europe-51588601>. Spain's lower house also passed a bill to legalise VAD which is being considered by the Senate: Sydney Morning Herald, 'Spanish Parliament votes to legalise euthanasia' (online, 18 December 2020) <https://www.smh.com.au/world/europe/spanish-parliament-votes-to-legalise-euthanasia-20201218-p56oll.html> . In Germany, in February 2020, the Constitutional Court declared § 217 of the *Strafgesetzbuch* [Criminal Code] (Germany) ('StGB'), which criminalised the provision of assisted suicide services, was unconstitutional: Bundesverfassungsgericht [German Constitutional Court], 2 BvR 2347/15, 26 February 2020 reported in (2020) BVerfG, Urteil des Zweiten Senats vom 26 Februar 2020, Rn 1-343.

[268] For an updated list of ongoing legislative activity in relation to VAD in the United States, see 'In Your State', *Death With Dignity* (Web Page, 2 August 2020) <https://www.deathwithdignity.org/in-your-state/>.

Australia, a particular issue is whether other states should follow the 'Victorian model', as Western Australia has substantially done, or take a different path.[269] There can be a tendency to adopt an existing framework, but uncritical acceptance of the Victorian approach must be avoided.[270] These comparative analyses raise important questions about the Victorian Act's[271] operation in practice, and provide other models for policy-makers to consider.

Further, the comparative practical analysis demonstrates the critical importance of testing the operation and boundaries of proposed VAD laws against a range of medical conditions. The exercise of determining which medical conditions might permit access to VAD, and when, as well as those medical conditions which would not be eligible for access to VAD, can help ensure frameworks operate as intended. Perhaps the most striking conclusion from this practical comparative analysis is how, putting aside Canada, different eligibility criteria appeared to make limited difference to access to VAD, and primarily only in relation to timing of that access. This suggests potential redundancy in some criteria. While some may argue that this redundancy does not matter (perhaps comfortable with this out of an abundance of caution), including criteria not required to control access to VAD can add unnecessary complexity and uncertainty to assessing eligibility. This can cause undesirable outcomes of inconsistency and undue conservatism in decision-making. Also important to

[269] Ben White and Lindy Willmott, 'Future of Assisted Dying Reform in Australia' (2018) 42(6) *Australian Health Review* 616.
[270] The *Victorian Act* (n 14) has been the subject of critical analysis from a range of normative perspectives including: its own stated regulatory goals (White et al, 'Does the VAD Act Reflect Its Stated Policy Goals?' (n 233)); ethical and legal values (Lindy Willmott, Katrine Del Villar and Ben White, 'Voluntary Assisted Dying in Victoria, Australia: A Values-Based Critique' in Sue Westwood (ed), *Regulating the Ending of Life: Death Rights* (Routledge, 2020)) and human rights (Lindy Willmott, Ben White and Katrine Del Villar, 'Voluntary Assisted Dying: Human Rights Implications for Australia' in Paula Gerber and Melissa Castan (eds), *Contemporary Perspectives on Human Rights Law in Australia* (Thomson, 2020) vol 2).
[271] *Victorian Act* (n 14).

consider when designing reform are those areas identified in this review as problematic or challenging. They included the question of whether a requirement for a time until death is appropriate, as well as the vexing issue of capacity and VAD.

These reflections also apply to jurisdictions with existing VAD laws. It is critical that the current law continues to be reviewed to see if it can be improved. Indeed, many jurisdictions when passing VAD laws have mandated that reviews of the legislation occur after a specified period of time.[272] Such a review should include issues that new jurisdictions would grapple with (as per above) but there is also scope after a VAD law is in operation to collect data about its functioning in practice. This data was considered in the analysis above, primarily for Canada and Oregon.[273] Generating concrete evidence about who is receiving access to VAD and who is being *refused* access helps determine whether eligibility criteria are operating as intended at the time the law passed. Such a review of how the law is being interpreted in practice also provides opportunities to support current approaches or correct them as needed. We have noted a range of regulatory tools that could be utilised to achieve this.

We can expect that VAD reform efforts will continue in Australia and overseas. And even if reform occurs and law passes, attention then shifts to carefully reviewing the operation of those laws in practice. The comparative legal and practical analyses undertaken in this two-paper series provide an opportunity to inform and support considered law reform and evaluation of that law in Australia and abroad.

[272] See *Victorian Act* (n 14) ss 116(1)–(3); *WA Act* (n 9) ss 164(1)–(2); model Bill (n 3) pt 9; Bill C-14 (n 6) ss 10(1)–(2); Bill C-7 (n 6) ss 3.1, 5.
[273] Fewer data were available at time of publication from Victoria.

COMPARATIVE AND CRITICAL ANALYSIS OF KEY ELIGIBILITY CRITERIA FOR VOLUNTARY ASSISTED DYING UNDER FIVE LEGAL FRAMEWORKS

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We disclose that Ben White and Lindy Willmott were engaged by both the Victorian and Western Australian Governments to design and provide the legislatively mandated training for doctors involved in voluntary assisted dying. Jayne Hewitt was the project manager for the Victorian training project and Rebecca Meehan, Laura Ley Greaves and Eliana Close were employed on the project. Eliana Close and Katrine Del Villar were also employed on the Western Australian training project. James Cameron was a Senior Legal Policy Officer at the Department of Health and Human Services (Victoria) and developed and implemented the *Voluntary Assisted Dying Act 2017* (Vic). Jocelyn Downie was a member of the Royal Society of Canada Expert Panel on End of Life Decision-Making, a member of the plaintiffs' legal team in *Carter v Canada (A-G)* [2015] 1 SCR 331, a member of the Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying and a member of the Council of Canadian Academies Expert Panel on Medical Assistance in Dying. Rebecca Meehan is an employee of Queensland Parliament, but this paper only represents her views. Ben White is a recipient of an Australian Research Council Future Fellowship (project number FT190100410: Enhancing End-of-Life Decision-Making: Optimal Regulation of Voluntary Assisted Dying) funded by the Australian Government. The authors gratefully acknowledge the research assistance of Emily Bartels.

ABSTRACT

Eligibility criteria determine a crucial question for all voluntary assisted dying frameworks: who can access assistance to die. This paper undertakes a critical and comparative analysis of these criteria across five legal frameworks: existing laws in Victoria, Western Australia, Oregon and Canada along with a model Bill for reform. Key aspects of these criteria analysed are capacity requirements; the nature of the medical condition that will qualify; and any required suffering. There are many similarities between the five models but there are also important differences which can have a significant impact on who can access voluntary assisted dying and when. Further, seemingly straightforward criteria can become complex in practice. The paper concludes with the implications of this analysis for designing voluntary assisted dying regulation. Those implications include challenges of designing certain yet fair legislation and the need to evaluate voluntary assisted dying frameworks holistically to properly understand their operation.

I INTRODUCTION

Internationally, voluntary assisted dying ('VAD') is permitted in an increasing number of jurisdictions. In Europe, VAD is legal in certain circumstances in the Netherlands,[2] Belgium[3] and Luxembourg.[4] Further, in Switzerland,[5] and more recently in Germany,[6] assisting a person to self-administer lethal medication in certain circumstances has been decriminalised. In the United States, there are now ten states and one district where VAD is lawful, with ten having legalised the practice by passing legislation[7] and one through judicial decision.[8] VAD is also permitted in Canada[9] and Colombia.[10]

[2] *Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001* (Netherlands).
[3] *Act on Euthanasia 2002* (Belgium).
[4] *Legislation Reglementant Les Soins Palliatifs Ainsi Que L'euthanasie Et L'assistance Au 2009* (Luxembourg).
[5] *SR 311 Schweizerisches Strafgesetzbuch* (Switzerland) art 115: 'Any person who for selfish motives incites or assists another to commit or attempt to commit suicide is, if that other person thereafter commits or attempts to commit suicide, liable to a custodial sentence not exceeding five years or to a monetary penalty'.
[6] Bundesverfassungsgericht [German Constitutional Court], 2 BvR 2347/15, 26 February 2020 reported in (2020) BVerfG, Urteil des Zweiten Senats vom 26 Februar 2020, Rn 1-343.
[7] *Death with Dignity Act*, Or Rev Stat §§ 127.800–127.995 (1994) (Oregon) ('*Oregon Act*'); *Death with Dignity Act*, Wash Rev Code §§ 70.245.010–70.245.904 (2008) (Washington); *Patient Choice and Control at End of Life Act*, Vt Stat Ann §§ 5281-93 (2013) (Vermont); *End of Life Option Act*, Cal Health and Safety Code §§ 443–443.22 (West 2015) (California); *Death with Dignity Act of 2016*, DC Code §7-661 (2017) (District of Columbia); *End-of-Life Options Act*, Colo Rev Stat § 25-48-101 (2017) (Colorado); *Our Care, Our Choice Act 2018*, Hawaii Rev Stat §§ 327-1–327-25 (2018) (Hawaii); *Medical Aid in Dying for the Terminally Ill Act*, NJ Stat Ann §§ 26:16-1–26:16-20 (2019) (New Jersey); *An Act to Enact the Maine Death with Dignity Act,* 22 Me Rev Stat Ann § 2140 (2019) (Maine); *Elizabeth Whitefield End-of-Life Options Act,* NM Stat § 3 (2021) (New Mexico).
[8] *Baxter v Montana*, 224 P 3d 1211 (Mont, 2009). Pope argues that VAD is also lawful in North Carolina, through a 'standard of care' approach. There is no legislation, regulation or court case that permits VAD, but VAD is not prohibited under current law. See Thaddeus Pope, 'Medical Aid in Dying: Key Variations Among U.S. State Laws' (2020) 14(1) *Journal of Health Sciences and Life Sciences Law* 25, 35.
[9] Across Canada through the *Criminal Code,* RSC 1985, c C-46, ss 241.1–241.4 ('Canadian *Criminal Code*') and in Quebec also through the *Act Respecting End-of-Life Care,* RSQ, c S-32.0001. The criteria in these laws are similar but not identical. However, because the federal law applies across the whole of Canada, this paper focuses on the eligibility criteria contained in the Canadian *Criminal Code*.
[10] A court decision in Colombia permitted VAD in 1997 *Judgment C-239 of 1997*, Republic of Colombia Constitutional Court, Ref Expedient # D-1490, 20 May 1997, which was followed by Government regulations to facilitate the practice in 2015: *Protocolo Para La Aplicación Del Procedimiento De Eutanasia En Colombia*: Government of Colombia, *Protocol for the Application of the Procedure of Euthanasia in Colombia* (Report, 2015) <https://www.minsalud.gov.co/sites/rid/Lists/BibliotecaDigital/RIDE/DE/CA/Protocolo-aplicacionprocedimiento-eutanasia-colombia.pdf>.

Australia too has seen law reform in this area. In November 2017, the *Voluntary Assisted Dying Act 2017* (Vic) ('Victorian Act') was passed. It came into force on 19 June 2019, permitting VAD in Australia for the first time in 20 years.[11] This was followed in December 2019 by the enactment of the *Voluntary Assisted Dying Act 2019* (WA) ('WA Act'), after an extensive parliamentary debate which followed reviews by a Parliamentary Committee[12] and a Ministerial Expert Panel.[13] These laws may herald a shift in political thinking, because despite a long history of unsuccessful attempts of reform,[14] it appears that the climate in Australia may now be more conducive to change.[15] As this article was being finalised for publication, Tasmania passed VAD legislation, [16] there is a Bill before the South Australian[17] and Queensland[18] parliament, and a Bill is also proposed in 2021 in New South Wales.[19]

A key policy question for Australian and international legislators when designing such laws is who should be permitted to access VAD. The primary means by which access is regulated is through eligibility criteria. Although generally only a small part of the legislation in terms of the number of provisions, eligibility criteria play a significant role in determining the breadth of

[11] VAD was briefly permitted in the Northern Territory by the *Rights of the Terminally Ill Act 1995* (NT) but this legislation was overturned later by the *Euthanasia Laws Act 1997* (Cth).
[12] Joint Select Committee on End of Life Choices, Parliament of Western Australia, *My Life, My Choice* (First Report, 23 August 2018).
[13] Government of Western Australia, Department of Health, Ministerial Expert Panel on Voluntary Assisted Dying, *Final Report* (Report, July 2019) ('*MEP Report*').
[14] For a detailed discussion of the history of attempts at law reform in Australia, see Lindy Willmott et al, '(Failed) Voluntary Euthanasia Law Reform in Australia: Two Decades of Trends, Models and Politics' (2016) 39(1) *University of New South Wales Law Journal* 1. See also updated data in Ben White and Lindy Willmott, 'Future of Assisted Dying Reform in Australia' (2018) 42(6) *Australian Health Review* 616 ('Future of Assisted Dying Reform').
[15] White and Willmott, 'Future of Assisted Dying Reform' (n 14).
[16] *End-of-Life Choices (Voluntary Assisted Dying) Act 2021* (Tas). This will take effect in October 2021, after a prescribed implementation period: s 2.
[17] Voluntary Assisted Dying Bill 2020 (SA).
[18] Voluntary Assisted Dying Bill 2021 (Qld).
[19] Michael Koziol, 'Fresh bid to legalise assisted dying set to test NSW government', *Sydney Morning Herald* (online, 13 December 2020) <https://www.smh.com.au/politics/nsw/fresh-bid-to-legalise-assisted-dying-set-to-test-nsw-government-20201209-p56m2t.html>.

VAD laws. Broad eligibility criteria exclude very few individuals from VAD, whereas narrow and tightly constrained criteria can significantly limit access.

This paper is the first in a two-part series[20] that critically analyses the scope and operation of eligibility criteria in five VAD legal frameworks. In particular, the papers consider these two questions: for what medical conditions, and at what stage in the trajectory of those conditions, would a person be eligible to access VAD? While eligibility criteria commonly contain provisions unrelated to a person's health state, such as residency and age requirements, the most contentious discussion when debating eligibility under VAD laws has been in relation to when, and with what medical conditions, a person could seek access to VAD.[21]

This first paper undertakes a critical analysis of the eligibility criteria outlined in five selected models of VAD, with a particular focus on those criteria that are relevant to a person's health state. Key aspects of those criteria are: the nature of the medical condition or illness a person must have, and the requirement to retain decision-making capacity when seeking VAD. The criteria in three Australian models have been chosen for review: the Victorian Act, the WA Act, and a model Voluntary Assisted Dying Bill 2019 ('model Bill')[22] recommended by the Queensland Parliamentary inquiry considering VAD as the proposed basis for reform.[23] The

[20] The second paper is Ben P White et al, 'Who is Eligible for VAD? Nine Medical Conditions Assessed Against Five Legal Frameworks' (2022) (forthcoming) ('Who is Eligible for VAD?').
[21] For example, in Victoria, the debate on the eligibility criteria ranged over people with neurological disease, an insulin-dependent diabetic who decides to stop taking insulin, renal disease, terminal cancer, people with disabilities, loneliness, incontinence, autism and mental illness: Victoria, *Parliamentary Debates,* Legislative Council, 21 November 2017, 6216–24, 6232–9. In Western Australia, the debate on the eligibility clause was briefer, but canvassed a person with gangrene who refused amputation, a diabetic who refuses insulin (Western Australia, *Parliamentary Debates,* Legislative Council, 26 November 2019, 9199–201), as well as people with autism and mental illnesses such as schizophrenia, anorexia and depression (Western Australia, *Parliamentary Debates,* Legislative Council, 22 October 2019, 7978–9).
[22] Ben White and Lindy Willmott, 'A Model Voluntary Assisted Dying Bill' (2019) 7(2) *Griffith Journal of Law and Human Dignity* 1 ('model Bill').
[23] Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee, Parliament of Queensland, *Inquiry into Aged Care, End-of-Life and Palliative Care and Voluntary Assisted Dying* (Report No 34, 31 March 2020) ('*Queensland Parliamentary Report*') 105, 'Recommendation 1'.

Victorian legislation has served as a basis for both the WA Act and the model Bill, although both incorporate important differences.

Additionally, the review includes two other important common law comparators.[24] The first is Oregon's *Death with Dignity Act 1994* ('Oregon Act').[25] It is the original legislation in the United States and has largely been copied by other states in that country. It was also cited as an important departure point when designing the Victorian model.[26] The second law considered is Canada's federal law about VAD (called 'MAiD': medical assistance in dying), which is contained in its *Criminal Code* ('Canadian *Criminal Code*').[27] Shared legal heritage means Canada is a natural comparator for Australia when considering law reform.[28] Canada's MAiD law has been considered, and Canadian experts consulted, in Australian reviews of VAD,[29] for example, in

[24] We note that the New Zealand Parliament passed its *End of Life Choice Act 2019* (NZ) in late 2019 (which would only take effect if approved by a public referendum, as subsequently occurred in late 2020). However, this occurred only after this analysis in this paper was finalised and accordingly, we will not consider this Act further. Also not included are the European models and Colombia. This is because these jurisdictions are culturally more distinct from Australia than other common law countries, and their laws operate within quite different legal systems.

[25] *Oregon Act* (n 7).

[26] For example, in relation to the eligibility criteria; preference for self-administration at a time of the person's choosing, without a medical practitioner needing to be present; a prescribed waiting period before VAD can be accessed; review and reporting: Legal and Social Issues Committee, Parliament of Victoria, *Inquiry Into End of Life Choices* (Final Report, 9 June 2016) 217–18, 228 ('*LSIC Report*'). There are also numerous references to similarities between the *Oregon Act* (n 7) and the proposed Victorian law in the Government of Victoria, Department of Health and Human Services, Ministerial Advisory Panel on Voluntary Assisted Dying, *Final Report* (Report, 31 July 2017) ('*MAP Report*'). See examples just in relation to the eligibility criteria: at 53, 55, 56, 63, 69.

[27] Canadian *Criminal Code* (n 9) ss 241.1–241.4. The Canadian law has undergone various iterations (including through amendments made through *An Act to amend the Criminal Code and to Make Related Amendments to Other Acts (Medical Assistance in Dying*)), SC 2016, c 3 ('Bill C-14') and *An Act to amend the Criminal Code (Medical Assistance in Dying)*, SC 2021 ('Bill C-7').

[28] White and Willmott, 'Future of Assisted Dying Reform' (n 14); Stephen Kirchner, Sean Speer and Jason Clemens, Fraser Institute, *Policy Reforms in Australia and What They Mean for Canada* (Report, December 2013) <https://ssrn.com/abstract=2392622>. See also, particularly in relation to reform of the common law by reference to United Kingdom and Canadian examples: *Cook v Cook* (1986) 162 CLR 376, 390 (Mason, Wilson, Deane and Dawson JJ); James Allsop, 'Some Reflections on the Sources of Our Law' (Conference Paper, Supreme Court of Western Australia Judges' Conference, 18 August 2012) 7–8.

[29] The Ministerial Expert Panel in WA met with four Canadian experts and one from Oregon in drafting the VAD legislation: *MEP Report* (n 13) 126. (Note that Quebec was also considered in Victoria's *MAP Report* (n 26)).

respect of its terminology requiring the person's medical condition to be 'incurable',[30] and in relation to the requirement of unbearable or intolerable suffering.[31]

After critically analysing each of the varying approaches to eligibility, this paper undertakes a comparative analysis of the five jurisdictions to identify important areas of similarity and difference. Although this work establishes the foundation for the consideration of medical conditions that follows in the second paper, this legal analysis is significant in its own right and has implications for designing VAD regulation, which are identified in section IV.

The second paper then applies this analysis to evaluate whether different medical conditions would be eligible for VAD under the five regimes. These conditions are: cancer (specifically colorectal cancer), motor neurone disease, chronic obstructive pulmonary disease, chronic kidney disease, dementia (specifically Alzheimer's disease), anorexia, spinal cord injury, Huntington's disease and frailty. This diverse group of conditions was chosen with a view to illustrating how the various eligibility criteria would apply in a range of settings. Regard was had to considerations such as those conditions most likely to be relied upon to access VAD, common causes of death in Australia, and conditions in the literature that have sparked controversy about access to VAD.

The analysis in the second paper demonstrates how changes in the framing of eligibility criteria can have an impact on who is included or excluded from accessing VAD, and at what point this access may be possible in their illness trajectory. This has implications for law reform, for example, when certain conditions may be seen by the public as important in the case for allowing VAD, but people with those conditions would not be eligible for VAD under the law as

[30] See, eg, *MEP Report* (n 13) 33–34 (although they did not adopt this criterion).
[31] See *LSIC Report* (n 26) 217.

drafted. Another conclusion from this research is that concrete thinking is needed when designing VAD laws. While criteria can be considered in the abstract, it is this practical exercise of ascertaining where eligibility criteria will draw lines that is critical. While these decisions have been made for Victoria and Western Australia as their Acts have passed, there is scope to inform the remaining Australian jurisdictions (and indeed other countries) considering VAD reform.

We conclude this introduction with two practical matters. The first is about the scope of analysis of the eligibility criteria. The focus of this two-part series is on the contentious issue of the impact that a person's medical condition has on their eligibility to access VAD. Accordingly, the analysis which follows emphasises criteria such as whether a condition is incurable or likely to cause death, and gives less consideration to other criteria, such as age and residency requirements.

The second practical matter is about terminology. In general, the terminology in relation to VAD used in the Victorian Act (and subsequently mirrored in the model Bill and the WA Act) will be adopted. VAD therefore includes both 'self-administration' (where the person takes the prescribed medication themselves, sometimes called physician-assisted suicide or dying) and 'practitioner administration' (where the person is administered the medication by a doctor, or nurse practitioner in Western Australia or Canada, sometimes called voluntary euthanasia). However, when considering Canadian law, the specific defined term used in that law (MAiD) will be used. The paper will also refer to a person's 'medical condition' and this is meant in a broad sense, whether that condition is caused by disease, illness, disability, or injury, although we note some VAD laws specifically address these latter concepts.

II ELIGIBILITY CRITERIA OF FIVE MODELS

A *Introduction*

This section outlines the eligibility criteria in the five VAD models: three Australian models in chronological order (the Victorian Act, the model Bill and the WA Act) and then the Oregon Act and the Canadian *Criminal Code*. As noted above, while all eligibility criteria are noted for completeness, this paper focuses on analysing those criteria particularly relevant to determining which medical conditions may provide access to VAD. A final point to note is that the Canadian eligibility criteria have been subject to extensive discussion, including academic commentary specifically aimed at interpreting these criteria, as well as some judicial and now legislative consideration, and this is reflected in the extended treatment of this jurisdiction's law below. By contrast, the Australian models are very new and have been subject to very limited critical analysis to date, and so are addressed more succinctly.

B *Voluntary Assisted Dying Act 2017 (Vic)*

The Victorian Act came into force on 19 June 2019 after a planned 18-month implementation period and permits access to VAD after a rigorous process that requires at least three requests from an eligible patient and at least two assessments by qualified and trained medical practitioners. VAD is intended usually to be self-administered, as practitioner administration is permitted only when a person is physically incapable of taking or digesting the medication themselves.[32] The Victorian law was described by the Victorian Government at the time of introduction to Parliament as the safest and most conservative VAD model in the world.[33]

[32] *Voluntary Assisted Dying Act 2017* (Vic) ss 46, 48 ('*Victorian Act*').
[33] Daniel Andrews, 'Voluntary Assisted Dying Model Established Ahead of Vote in Parliament' (Media Release, Premier of Victoria, 25 July 2017) 1 <https://www.premier.vic.gov.au/voluntary-assisted-dying-model-established-ahead-of-vote-in-parliament/> ('Andrews Media Release').

Part of this claim is based on the Act's eligibility criteria. Section 9(1) of the Victorian Act outlines the primary eligibility criteria and states that '[f]or a person to be eligible for access to voluntary assisted dying':

> (a) the person must be aged 18 years or more; and
>
> (b) the person must—
>
> > (i) be an Australian citizen or permanent resident; and
> >
> > (ii) be ordinarily resident in Victoria; and
> >
> > (iii) at the time of making a first request, have been ordinarily resident in Victoria for at least 12 months; and
>
> (c) the person must have decision-making capacity in relation to voluntary assisted dying; and
>
> (d) the person must be diagnosed with a disease, illness or medical condition that—
>
> > (i) is incurable; and
> >
> > (ii) is advanced, progressive and will cause death; and
> >
> > (iii) is expected to cause death within weeks or months, not exceeding 6 months [or 12 months if the disease, illness or medical condition is neurodegenerative];[34] and
> >
> > (iv) is causing suffering to the person that cannot be relieved in a manner that the person considers tolerable.

Section 9 continues and clarifies that disability and mental illness alone are not grounds to access VAD.[35] However, the mere fact of a disability or a mental illness will not preclude a person from accessing VAD if the eligibility criteria are met.[36]

[34] Note that the additional words in square brackets are located in *Victorian Act* (n 32) s 9(4).
[35] Ibid ss 9(2)–(3).
[36] *MAP Report* (n 26). See 'Ministerial Panel Recommendation 5' in respect of mental illness: at 80–82. See also 'Ministerial Panel Recommendation 6' in respect of disability: at 83–5.

1 *Decision-Making Capacity*

Subsection 9(1)(c) requires the person to have decision-making capacity in relation to VAD and this is assessed at multiple points during the process.[37] If VAD is provided by practitioner administration, capacity is also specifically assessed at that final point in time. For self-administration, capacity is assessed at each stage during the request and assessment process but not at the time of ingestion, as this is done later at a time of the person's choosing and without a practitioner necessarily being present.

A person has decision-making capacity if they meet four requirements. The person must be able to understand the relevant information, retain that information, use or weigh the information as part of a decision-making process, and communicate their decision.[38] There is a presumption that an adult has decision-making capacity, and to displace that presumption, it must be demonstrated they do not meet one of the four requirements.[39] Under the legislation, a person is unable to make a request for VAD in advance of losing decision-making capacity by means of an advance directive.[40]

The decision-making capacity assessment only requires doctors to assess whether the person meets the four requirements, not whether they consider the person's decision to be wise.[41] The limited basis on which a doctor may determine a person does not have decision-making capacity is further explained in the *Guidance for Health Practitioners* produced by the Victorian Department of Health and Human Services.[42] As that document makes clear, the presence of

[37] *Victorian Act* (n 32) ss 16, 25, 36, 47, 48, 64.
[38] Ibid s 4.
[39] Ibid s 4(2).
[40] Ibid s 140.
[41] Ibid s 4(4)(c).
[42] Department of Health and Human Services, Government of Victoria, *Voluntary Assisted Dying: Guidance for Health Practitioners* (Clinical Guideline, July 2019) 34 <https://www2.health.vic.gov.au/hospitals-and-health-

depression or other mental illness does not necessarily mean a person lacks decision-making capacity. What is being assessed is whether the person meets the four requirements listed and mental illness does not necessarily prevent this.

Consistent with other Victorian legislation,[43] the Victorian Act also recognises decision-making capacity is decision specific, that information may be tailored to meet a person's particular needs, and that people may be supported to make decisions. The Act adopts an inclusive approach to assessing decision-making capacity, recognising that people may understand or communicate things in different ways and that this does not necessarily mean they cannot make decisions for themselves.[44] The Act also recognises a person may have decision-making capacity if they are able to make a decision through the use of practicable supports.[45] These provisions recognise people using non-standard forms of communication or receiving some form of support should not be excluded from accessing VAD on this basis.

2 ***Disease, Illness or Medical Condition that is Incurable***

Subsection 9(1)(d)(i) of the Victorian Act requires the relevant disease to be 'incurable'. The Explanatory Memorandum explains that this assessment is based on the individual's circumstances and co-morbidities, but whether a disease is 'incurable' is a question of 'whether there is a clinically indicated treatment that will cure the disease'.[46] During the Parliamentary

services/patient-care/end-of-life-care/voluntary-assisted-dying/coordinating-consulting-medical-practitioner-information> ('*Guidance for Health Practitioners*').

[43] See, eg, *Medical Treatment Planning and Decisions Act 2016* (Vic) s 4; *Powers of Attorney Act 2014* (Vic) s 4.

[44] *Victorian Act* (n 32) s 4(3).

[45] Ibid s 4(4)(d).

[46] Explanatory Memorandum, Voluntary Assisted Dying Bill 2017 (Vic) cl 9 ('Explanatory Memorandum, VAD Bill (Vic)').

debate, Minister Jennings further clarified this by stating that '[t]his is an objective test based on available medical treatments'.[47]

The Explanatory Memorandum also recognises that '[t]here is a difference between *managing* the symptoms of a disease, illness, or medical condition and *curing* it, which requires the complete eradication of the disease, illness or medical condition [emphasis added]'.[48] For example, renal dialysis manages kidney disease, but it does not cure the disease. The fact that a person refuses treatment for a curable disease does not make it incurable (although refusing treatment may allow the condition to progress to the point that it becomes incurable). This suggests the assessment of whether a disease is incurable is a medical assessment based on available treatments and that a person will not be eligible if they are refusing treatment for an otherwise curable condition.

3 ***Disease, Illness or Medical Condition that is Advanced and Progressive***

It is not sufficient that a disease is incurable; it must also be advanced and progressive.[49] These criteria mean the person's condition must be deteriorating and this deterioration must be at an advanced stage.

Neither the term 'advanced' nor the term 'progressive' is defined. The Department of Health and Human Services *Guidance for Health Practitioners* suggests a condition will be progressive if 'the patient is experiencing an active deterioration'.[50] Applying the ordinary meaning of the term 'advanced' suggests the condition must have significantly progressed along its expected trajectory. When applied in conjunction with the term 'progressive', it must be expected the

[47] Victoria, *Parliamentary Debates*, Legislative Council, 21 November 2017, 6218 (Gavin Jennings).
[48] Explanatory Memorandum, VAD Bill (Vic) (n 46) cl 9.
[49] *Victorian Act* (n 32) s 9(d)(ii)
[50] *Guidance for Health Practitioners* (n 42) 37.

person will continue to decline along this trajectory. This would prevent access by people in the earlier stages of a terminal condition. The extent to which a condition is advanced and progressive may also cause confusion, as both criteria are ultimately a question of degree and one may ask how far advanced a condition needs to be or what constitutes progression. In practice the effect of these criteria and any potential confusion are likely to be limited though. This is because of the further requirement that death must be expected within six months (or 12 months for a neurodegenerative condition). In order to meet these timeframes, it is likely the person's condition would be advanced and progressive, which gives context to what is meant by these terms.

4 *Disease, Illness or Medical Condition that Will Cause Death and is Expected to Cause Death Within Six or Twelve Months*

The relevant condition must be one that will cause death. The necessary connection between the condition and the ultimate cause of death has not been explained in either Parliamentary debates or subsequent health policies. For many conditions, death may be the result of organ failure that is a predictable but not a necessary outcome of the condition. For example, a metastatic cancer may hinder the functioning of the digestive system, which may result in malnourishment and dehydration that causes death. It is suggested that the requirement that a condition will cause death will be fulfilled if the condition will cause a chain of events that will result in death.

Under subsection 9(1)(d)(iii) of the Victorian Act, the medical condition must be expected to cause death within six months, except in the case of neurodegenerative conditions where the relevant time is 12 months. The assessment of this criterion is complex because 'most prognostication tools have been developed to assist in identifying patients' needs and to plan

care and support, not for determining a timescale for death'.[51] The words 'expected to' in this criterion appear to recognise prognosis is not an exact science and cannot be as definitive as some of the other eligibility criteria.

While the requirement for the condition to be 'incurable' must be based on an objective assessment of clinically indicated treatments, an assessment of whether the disease will cause death and will do so within the requisite timeframe must consider the individual and the treatments acceptable to them. The Explanatory Memorandum explains that, in assessing the timeframe within which a person is expected to die, a medical practitioner must consider the 'individual's own particular circumstances, including their condition, their comorbidities, and the available treatments that they are prepared to accept, noting the right to refuse medical treatment'.[52] This recognises that conditions progress in different ways in different people. It also recognises that if a person has an incurable condition but there are treatments that could slow the progress of that disease, they should not be required to undergo all such treatments prior to accessing VAD. For example, a person who chooses not to undergo further chemotherapy for quality of life reasons may still be eligible for VAD even if that treatment may temporarily prolong their life.

5 ***Disease, Illness or Medical Condition is Causing Suffering***

The final criterion in subsection 9(1)(d)(iv) of the Victorian Act is that the condition must be causing suffering that cannot be relieved in a manner deemed tolerable by the person. The use of the term 'suffering' recognises that a condition may cause more than physical pain to a person, and that existential distress or other forms of suffering caused by the condition may

[51] Ibid 38.
[52] Explanatory Memorandum, VAD Bill (Vic) (n 46) cl 9.

also be sufficient.[53] This assessment has two parts. First, the person's suffering must be caused by their condition. Second, the suffering must not be able to be relieved in a manner deemed tolerable by the person. Whether suffering can be relieved is a 'subjective' assessment, assessed by the person.[54]

C *Model Voluntary Assisted Dying Bill 2019*

The model Bill was written by two of the authors and publicly released in April 2019 as a submission to the Queensland Parliament's inquiry into aged care, end-of-life and palliative care and voluntary assisted dying.[55] The final report from that inquiry recommended that the Queensland Government use the Bill 'as the basis for a legislative scheme for voluntary assisted dying'.[56] The goal of the model Bill was to state preferred policy positions on VAD and represent those positions in the concrete form of a draft Bill that could be considered by jurisdictions undertaking reform. Although initially submitted to a Queensland law reform exercise, the model Bill was written not only for that State and was proposed for consideration by other Australian States too.

The model Bill is based on a series of values that had been articulated earlier as appropriate to guide design of a VAD law.[57] The values articulated as relevant were: life; autonomy; freedom

[53] *Guidance for Health Practitioners* (n 42) 39.
[54] Explanatory Memorandum, VAD Bill (Vic) (n 46) cl 9; see also Victoria, *Parliamentary Debates*, Legislative Assembly, 21 September 2017, 2949 (Jill Hennessy) ('*VAD Bill Second Reading Speech*').
[55] The model Bill (n 22) was first published as a submission at https://eprints.qut.edu.au/128753/ in April 2019 and was subsequently published as Ben White and Lindy Willmott, 'A Model Voluntary Assisted Dying Bill' (2019) 7(2) *Griffith Journal of Law and Human Dignity* 1.
[56] *Queensland Parliamentary Report* (n 23) 105, 'Recommendation 1'. The model Bill (n 22) was also referred to in the Western Australian reform process: *MEP Report* (n 13) 78. The model Bill (n 22) is currently being considered by the Queensland Law Reform Commission as part of its role in developing proposed VAD legislation: Queensland Law Reform Commission, *Queensland's Laws Relating to Voluntary Assisted Dying* (Terms of Reference, 2020) <https://www.qlrc.qld.gov.au/__data/assets/pdf_file/0004/651379/vad-tor.pdf> ('QLRC Terms of Reference')).
[57] These values are set out in Lindy Willmott and Ben White, 'Assisted Dying in Australia: A Values-based Model for Reform' in Ian Freckelton and Kerry Peterson (eds), *Tensions and Traumas in Health Law* (Federation Press, 2017) ('Assisted Dying in Australia').

of conscience; equality; rule of law; protecting the vulnerable; and reducing human suffering. In addition, influenced by the Victorian Ministerial Advisory Panel,[58] added to this list was the concept of safe and high-quality care.[59]

The model Bill also drew heavily on the Victorian Act, recognising that the Act had already been subject to intense scrutiny when debated and passed by an Australian Parliament. (The WA Act was not released at the time and so could not be considered.) Accordingly, the Bill adopted or adapted the drafting of the Victorian Act where the model Bill's policy position was the same or similar. However, the application of these values did lead to some key differences between the Victorian Act and the model Bill.[60] One key difference is that the model Bill proposes that people be given a choice between self-administration and practitioner administration, and that VAD be medically supervised.[61] There are also some differences in relation to eligibility criteria.

Clause 9 of the model Bill contains the eligibility criteria for access to VAD:

> (a) the person must be aged 18 years or more; and
>
> (b) the person must—
>
> (i) be an Australian citizen or permanent resident; and
>
> (ii) be ordinarily resident in [State]; and
>
> (c) the person must have decision-making capacity in relation to voluntary assisted dying; and
>
> (d) the person's decision to access voluntary assisted dying must be—
>
> (i) enduring;
>
> (ii) made voluntarily and without coercion; and

[58] *MAP Report* (n 26) 11, 22, 46. See also Ben P White et al, 'Does the Voluntary Assisted Dying Act 2017 (Vic) Reflect its Stated Policy Goals?' (2020) 43(2) *University of New South Wales Law Journal* 417 ('Does the VAD Act (Vic) Reflect its Stated Policy Goals?').
[59] Explanatory Notes, Model Bill (n 22).
[60] Ibid.
[61] Model Bill (n 22) cl 6.

(e) the person must be diagnosed with a medical condition that—

(i) is incurable; and

(ii) is advanced, progressive and will cause death; and

(iii) is causing intolerable and enduring suffering.

Clause 10 then clarifies certain aspects of the eligibility criteria. One clarification is that whether a person's medical condition will cause death is to be 'determined by reference to available medical treatment that is acceptable to the person'.[62] This is consistent with the Victorian position above but is made explicit in the Bill. The other clarifications relate to the nature of suffering required and stipulate that suffering:[63]

- is to be subjectively determined (again consistent with the Victorian Act but explicitly stated in the Bill);
- includes suffering caused by treatment for the medical condition; and
- includes physical, psychological and existential suffering (again explicit in the Bill but consistent with the Victorian approach).

Because of the model Bill's similarity with the Victorian Act, the focus of the discussion here will be on the ways in which the model Bill is different on the issue of eligibility. It is anticipated that, given the intentional use of the same or similar wording as in the Victorian Act, the analysis outlined above would also be generally applicable to the model Bill.

The most significant difference in relation to eligibility is that the Bill does not include the Victorian requirement that death is expected within a specified time frame. It was considered that a specified time limit is arbitrary.[64] Further, while a secondary consideration, not imposing

[62] Ibid cl 10(1).
[63] Ibid cl 10(2).
[64] Explanatory Notes, Model Bill (n 22); Willmott and White, 'Assisted Dying in Australia' (n 57).

a time limit avoids a registered medical practitioner having to engage in the difficult task of determining prognosis and timing of death.[65] In this way, the model Bill is wider than the Victorian Act in that it does not limit access to VAD to a window of temporal proximity to death. However, despite the absence of a time limit, the model Bill's other requirements cumulatively operate to restrict eligibility to persons suffering with an advanced, progressive and incurable medical condition that will cause death.

The model Bill also differs from the Victorian Act in relation to suffering. It requires 'intolerable and enduring suffering', which is arguably higher than the level of suffering required under the Victorian legislation.

Another difference relevant to the medical conditions that may be eligible for access to VAD is the definition of decision-making capacity. Clauses 7(1) and (2) of the model Bill define capacity in terms that correspond to the Victorian definition in sections 4(1) and (2) of that Act. However, the model Bill does not include the extended explanation of capacity contained in the Victorian Act as noted above, for example, in relation to supported decision-making. The model Bill's requirement that VAD be medically supervised also has implications for capacity in that immediately prior to VAD being provided, whether by self-administration or practitioner administration, the registered medical practitioner must ensure the person requesting VAD still has capacity.[66]

There are two final differences which are noted for completeness but are unlikely to impact on whether or not a person's medical condition will satisfy the eligibility requirements. One is that the model Bill includes, as part of its eligibility criteria, a requirement that the person's decision

[65] Explanatory Notes, Model Bill (n 22); Willmott and White, 'Assisted Dying in Australia' (n 57).
[66] Model Bill (n 22) pt 4 div 2.

to access VAD is enduring and made voluntarily and without coercion. While the Victorian Act does require assessment of these factors at various points during the request and assessment process,[67] this is not part of its formal eligibility criteria. In practice, this may not be significant given this aspect of decision-making is assessed under both systems. The other difference is residency. Under the model Bill, only one of Victoria's residency requirements is included: namely, being a resident of the State. There is no 12-month residency limit prior to a first request being made for VAD.

D *Voluntary Assisted Dying Act 2019 (WA)*

Following extensive consultation over a two-year period, the Voluntary Assisted Dying Bill 2019 (WA) was introduced into the Western Australian Parliament in August 2019 and after lengthy debate was passed in December 2019.[68] The WA Act broadly follows the approach of the Victorian Act. Some departures from the Victorian Act were designed to accommodate differences in the geography and demography of Western Australia.[69] Other departures reflect different policy positions. One notable example is that although the WA Act retains self-administration as the default approach, in some circumstances, practitioner administration can be chosen by a person, in consultation with their medical practitioner. This can occur where the medical practitioner advises the person that self-administration would be inappropriate having regard to the person's ability to self-administer, the person's concerns about it, and the most suitable method of VAD for the patient.[70]

[67] *Victorian Act* (n 32) ss 20(1)(c), 29(1)(c), 34(2)(a)(i).
[68] Between August 2017–18, a Joint Select Committee inquired into end of life choices for Western Australians. The Committee recommended the introduction of voluntary assisted dying legislation, and in support of this recommendation the Government appointed a Ministerial Expert Panel to consult and develop a legislative framework for WA. The Panel's report was tabled in Parliament on 27 June 2019: see *MEP Report* (n 13).
[69] Western Australia, *Parliamentary Debates,* Legislative Assembly, 7 August 2019, 5136 (Roger Cook, Minister for Health). The most significant of these was to allow for the use of telehealth in certain circumstances.
[70] *Voluntary Assisted Dying Act 2019* (WA) s 56(2) ('*WA Act*').

The differences between the Victorian Act and the WA Act in terms of eligibility criteria are more subtle. Subsection 16(1) of the WA Act contains the eligibility criteria that must be met for access to VAD:

a) the person has reached 18 years of age;

b) the person —

   (i) is an Australian citizen or permanent resident; and

   (ii) at the time of making a first request, has been ordinarily resident in Western Australia for a period of at least 12 months;

c) the person is diagnosed with at least 1 disease, illness or medical condition that—

   (i) is advanced, progressive and will cause death; and

   (ii) will, on the balance of probabilities, cause death within a period of 6 months or, in the case of a disease, illness or medical condition that is neurodegenerative, within a period of 12 months; and

   (iii) is causing suffering to the person that cannot be relieved in a manner that the person considers tolerable;

d) the person has decision-making capacity in relation to voluntary assisted dying;

e) the person is acting voluntarily and without coercion; and

f) the person's request for access to voluntary assisted dying is enduring.

As in Victoria, the WA Act states that disability and mental illness alone are not grounds to access VAD.[71] However, also like in Victoria, extrinsic material confirms that provided the eligibility criteria are met, the presence of a disability or a mental illness in itself will not preclude a person from accessing VAD.[72]

[71] Ibid s 16(2).
[72] Explanatory Memorandum, Voluntary Assisted Dying Bill (WA) 6 ('Explanatory Memorandum, VAD Bill (WA)').

Because the eligibility criteria in the WA Act are so similar to those in the Victorian Act, the remaining discussion will focus on key areas of difference, and where appropriate, comparisons with the model Bill.[73] A key difference between the WA Act and both the Victorian Act and model Bill is that in Western Australia there is no requirement for an eligible condition to be 'incurable'. In Victoria, whether or not a disease, illness or condition is incurable is viewed as an objective test based on available medical treatments.[74] This explanation was provided in the context of discussion about the ability of medical practitioners to accurately prognosticate about how long a person may have to live.[75] The presence of an incurable illness that was advanced and progressive would strongly indicate that the end of life was near. In considering a legislative framework for WA, the Ministerial Expert Panel ('MEP') did not specifically engage with the concept of an incurable disease[76] but instead explored whether a person should have a 'terminal' condition in order to be eligible to access VAD.[77] They formed the view that including a criterion that an illness or disease is 'advanced, progressive and will cause death' clearly 'emphasise[s] the terminal nature of the illness or disease' .[78] Consequently, further qualification of the type of illness, disease or condition was not seen as being required, and the WA Act does not refer to an 'incurable' condition. In debate on the Bill, the Government indicated that they considered the term 'incurable' just reiterated existing criteria.[79] The

[73] One minor difference noted but not considered further is that the *WA Act* (n 70), like the *Victorian Act* (n 32), requires a person to be ordinarily resident in the State for at least 12 months before the first request for VAD, but it does not repeat the (superfluous) requirement in the Victorian Act to also be ordinarily resident in the State.
[74] Victoria, *Parliamentary Debates*, Legislative Counsel, 21 November 2017, 6218 (Gavin Jennings).
[75] Ibid.
[76] Although the MEP did refer to the fact that Canada's and Luxembourg's laws require an incurable condition: *MEP Report* (n 13) 33.
[77] Ibid 32.
[78] Ibid 34.
[79] Western Australia, *Parliamentary Debates*, Legislative Council, 26 November 2019, 9200 (Stephen Dawson). See also Western Australia, *Parliamentary Debates*, Legislative Assembly, 5 September 2019, 6586 (Mark McGowan).

Premier Mark McGowan also observed that including a criterion of 'incurable' might require a person to undergo treatment they wish to refuse, or exhaust all treatment options,[80] potentially including experimental treatment in 'some far-flung place around the world'.[81] This would be 'contrary to a fundamental principle of patient autonomy'.[82]

In contrast, providing a timeframe within which a person is expected to die, was seen as an important safeguard in the legislative framework.[83] The model Bill does not require medical practitioners to engage with the challenging problem of estimating when a person might die, in part, because any suggested time frame would be arbitrary. While substantially reflecting the Victorian Act, the WA Act seeks to address the prognostic challenge of estimating when a person might die by requiring the assessment of life expectancy on the balance of probabilities.[84] That is, a medical practitioner must be satisfied that it is more likely than not[85] that the person will die within six months (or 12 months in the case of a person with a neurodegenerative condition).[86] In determining if a disease, illness or condition is likely to cause the death of a person, the medical practitioner can take account of the person's individual circumstances, their comorbidities and their treatment choices,[87] making it more than a pure mathematical exercise in probabilities. Traditionally, the 'balance of probabilities' has been reserved for tribunals trying to determine particular facts from competing or contradictory claims.[88] Parliamentary debate sheds little light on this terminology, other than to observe that

[80] Western Australia, *Parliamentary Debates*, Legislative Assembly, 5 September 2019, 6586 (Mark McGowan). See also Western Australia, *Parliamentary Debates*, Legislative Council, 26 November 2019, 9200 (Stephen Dawson).
[81] Western Australia, *Parliamentary Debates*, Legislative Council, 26 November 2019, 9200 (Stephen Dawson).
[82] Western Australia, *Parliamentary Debates*, Legislative Assembly, 5 September 2019, 6603 (Roger Cook).
[83] *MEP Report* (n 13) 35.
[84] *WA Act* (n 70) s 16(1)(c)(ii).
[85] John Dyson Heydon, *Cross on Evidence* (LexisNexis Butterworths, 11th ed, 2017) 395–397.
[86] *WA Act* (n 70) s 16(1)(c)(ii).
[87] Explanatory Memorandum, VAD Bill (WA) (n 70) 5 cl 15.
[88] James Allsop et al, 'Are You Sure?' (2019) 47(2) *Australian Bar Review* 124.

'the test is easily understood and has case law to support it',[89] and is commonly used and well understood by medical practitioners.[90] The MEP originally recommended the use of the phrase 'reasonably foreseeable', and did not mention 'balance of probabilities'.[91] However, legal officers within the government felt that 'reasonably foreseeable' was not clear enough, and that 'balance of probabilities' provided the 'greatest clarity and most utility'.[92] How it does so, and how or if it differs from 'expected' or 'reasonably foreseeable' was not explained. It was confirmed, however, in Parliamentary debates that this new wording was not intended to import a lower standard than is contained in the Victorian Act.[93]

The WA Act, like the Victorian Act and the model Bill, requires a person seeking access to VAD to have decision-making capacity in relation to VAD and requires capacity to be assessed at several points throughout the process. Like Victoria, the final assessment of capacity occurs at the point of practitioner administration, or for self-administration, at the conclusion of the request and assessment process (but not at the time of later ingestion). The WA Act, however, defines decision-making capacity in slightly different terms from the Victorian Act,[94] presumably to promote consistency with other Western Australian legislation defining decision-making capacity.[95] However, the similarity in approach means that its effect is likely to be the same. The WA Act, like the model Bill, also does not have the extended explanation of capacity found in the Victorian Act.

[89] Western Australia, *Parliamentary Debates*, Legislative Assembly, 5 September 2019, 6582 (Mark McGowan); Western Australia, *Parliamentary Debates*, Legislative Assembly, 5 September 2019, 6606 (Roger Cook).
[90] Western Australia, *Parliamentary Debates*, Legislative Assembly, 5 September 2019, 6606 (Roger Cook); Western Australia, *Parliamentary Debates*, Legislative Council, 26 November 2019, 9196 (Stephen Dawson).
[91] *MEP Report* (n 13) 36–9.
[92] Western Australia, *Parliamentary Debates*, Legislative Assembly, 5 September 2019, 6606-6607 (Roger Cook); Western Australia, *Parliamentary Debates*, Legislative Council, 26 November 2019, 9196 (Stephen Dawson).
[93] Western Australia, *Parliamentary Debates*, Legislative Council, 26 November 2019, 9196 (Stephen Dawson).
[94] *WA Act* (n 70) s 6.
[95] See, eg, *Mental Health Act 2014* (WA) s 15.

For completeness, it is noted that the WA Act mirrors the model Bill in including a requirement that the person's decision to access VAD must be enduring, made voluntarily and without coercion as part of the eligibility criteria.[96] Although different from the Victorian Act, as suggested above, the practical effect of this difference is likely to be insignificant.

E *Death with Dignity Act (Oregon)*

The Oregon Act[97] was passed through a ballot initiative process. At the November 1994 election, Oregon's citizens voted directly to approve the law by 51 to 49 percent.[98] However, a series of constitutional challenges delayed the implementation of the law by three years,[99] until the injunction against the operation of the law was lifted on 27 October 1997.[100] In November 1997, Oregonians rejected a direct ballot designed to repeal the Oregon Act, by a margin of 60 to 40 percent.[101] The law has been operational since that time.[102]

[96] *WA Act* (n 70) ss 16(1)(e), (f).
[97] *Oregon Act* (n 7).
[98] Patrick M Curran Jr, 'Regulating Death: Oregon's Death with Dignity Act and the Legalization of Physician-Assisted Suicide' (1998) 86(3) *Georgetown Law Journal* 725, 728.
[99] It was argued that the legislation violated a number of constitutional rights, including due process and equal protection rights under the Fourteenth Amendment; the free exercise of religion and freedom of association rights under the First Amendment; and statutory rights under the *Americans with Disabilities Act of 1990*, 42 USC §§ 12101–213; section 504 of the *Rehabilitation Act of 1973*, 29 USC §§ 701–97; and the *Religious Freedom Restoration Act of 1993*, 42 USC §§ 2000bb–bb4. The District Court of Oregon found the Act violated the equal protection clause, and issued injunctions preventing the law commencing: *Lee v Oregon*, 869 F Supp 1491 (D Or, 27 December 1994) (issuing preliminary injunction); *Lee v Oregon* 891 F Supp 1429 (D Or, 3 August 1995) (equal protection opinion); 891 F Supp 1439 (D Or, 3 August 1995) (issuing permanent injunction). On appeal, the Ninth Circuit Court held that the plaintiffs lacked standing: *Lee v Oregon* 107 F 3d 1382 (9th Cir, 17 February 1997), and the Supreme Court refused leave to appeal: *Lee v Harcleroad* 522 US 927 (14 October 1997). For discussion of these cases, see Brian Boyle, 'The Oregon Death with Dignity Act: A Successful Model or a Legal Anomaly Vulnerable to Attack' (2004) 40(5) *Houston Law Review* 1387, 1393–5.
[100] Curran (n 98) 729; Boyle (n 99) 1391.
[101] Curran (n 98) 729; Raphael Cohen-Almagor and Monica G. Hartman, 'The Oregon Death with Dignity Act: Review and Proposals for Improvement' (2001) 27(2) *Journal of Legislation* 269, 274.
[102] The law has been subject to, and survived, later litigation not directly challenging the statute itself, but alleging that a medical practitioner who prescribed drugs for assisted dying was not prescribing for a 'legitimate medical purpose' within the meaning of the federal *Controlled Substances Act*, 21 USC §§ 821–32, and consequently risked having his or her registration revoked: *Oregon v Ashcroft* 192 F Supp 2d 1077 (D Or, 2002); *Oregon v Ashcroft* 368 F 3d 1118 (9th Cir, 2004); *Gonzales v Oregon* 546 US 243 (2006). For discussion of these cases, see Boyle (n 99) 1396–9.

The Oregon Act, on which legislation in other US states is based,[103] has a rigorous assessment process that has been described as 'so carefully crafted, so narrowly drawn, and so laden with procedural safeguards that it may well demand more energy and fortitude to comply with it than some terminally ill people are likely to have.'[104] The model of VAD in Oregon is restricted to a doctor prescribing medication which the patient self-administers. There is no provision for practitioner administration.

The Oregon Act provides that to be eligible to request assistance to die a person must be:[105]

> An adult who is capable, is a resident of Oregon, and has been determined by the attending physician and consulting physician to be suffering from a terminal disease, and who has voluntarily expressed his or her wish to die.

Age or disability is specifically noted as being insufficient, of itself, to qualify for assistance to die.[106] Each of the Act's eligibility criteria, aside from being an adult and residence, will be considered separately below.

1 *Capacity*

To make a request for VAD a person must be 'capable', which is defined as having 'the ability to make and communicate health care decisions to health care providers'.[107] Communication can be made through persons familiar with the patient's manner of communicating if necessary. Capacity must be assessed by the patient's attending physician and consulting physician in every case before VAD is authorised,[108] and may additionally be evaluated by a psychiatrist or

[103] See above n 7 for the legislation in other US states.
[104] Alan Meisel, Kathy Cerminara and Thaddeus Pope, *The Right to Die: The Law of End-of-Life Decisionmaking* (Wolters Kluwers, 3rd ed, 2016) 12–91 §12.06[A][1].
[105] *Oregon Act* (n 7) § 127.805(1).
[106] Ibid § 127.805(2).
[107] Ibid § 127.800(3).
[108] Ibid §§ 127.815(1)(a), 127.820.

psychologist if there is concern that the person might be 'suffering from a psychiatric or psychological disorder or depression causing impaired judgment.'[109] The Oregon Act does not allow a person to request VAD in an advance directive.[110] While the person must have decision-making capacity at the time of the request and assessment process, capacity does not need to be assessed again at the point a person ingests the medication.[111]

2 *Terminal Disease*

A person must be 'suffering from a terminal disease'[112] to be eligible to receive assistance to die in Oregon. 'Terminal disease' is defined to mean 'an incurable and irreversible disease that has been medically confirmed and will, within reasonable medical judgment, produce death within six months.'[113] This means that a person with a chronic illness, such as Parkinson's disease or multiple sclerosis, which is incurable but will not of itself result in death, is not eligible under the legislation.[114]

'Medically confirmed' means that the diagnosis of a terminal disease is determined by two doctors: the attending physician and the consulting physician. The 'attending physician' is the doctor who has primary responsibility for the care of the patient and treatment of the terminal disease.[115] The attending physician makes the initial diagnosis that the disease is terminal. This

[109] Ibid § 127.825. These words were added by amendments in 1999: Meisel, Cerminara and Pope (n 104) 12–92.4 §12.06[A][1]. The Act specifically prohibits access to VAD for this cohort being evaluated until it is determined that 'the patient is not suffering from a psychiatric or psychological disorder or depression causing impaired judgment': *Oregon Act* (n 7) § 127.825. As to the role of depression in impairing decision-making, see Linda Ganzini, 'Legalised Physician-Assisted Death in Oregon' (2016) 16(1) *QUT Law Review* 76, 81–3.
[110] See Ganzini (n 109) 77.
[111] Note that Ganzini (n 109) raises concern about the possibility a person may have lost capacity by that stage: at 81.
[112] *Oregon Act* (n 7) § 127.805(1).
[113] Ibid § 127.800(12).
[114] This distinction is made by IG Finlay and R George, 'Legal Physician-Assisted Suicide in Oregon and The Netherlands: Evidence Concerning the Impact on Patients in Vulnerable Groups—Another Perspective on Oregon's Data' (2011) 37(3) *Journal of Medical Ethics* 171.
[115] *Oregon Act* (n 7) § 127.800(2).

medical opinion is then confirmed by a consulting physician, after examining the patient and the patient's relevant medical records.[116]

Neither 'incurable' nor 'irreversible' is defined, so it is unclear whether the statute would include a person who refused available medical treatment which has a chance of curing or reversing the process of disease, thus rendering an otherwise non-fatal condition terminal.[117] Oregon's *Guidebook for Health Care Professionals* suggests that '[d]oubts concerning the patient's diagnosis, prognosis, and volition should be resolved against provision of medication':[118] that is, where the doctor is uncertain whether or not the patient qualifies as terminally ill, they should refuse a request for VAD. However, this guidance does not directly address the issue of treatment refusal. In practice, the application of 'incurable and irreversible' may vary according to the condition from which the person is suffering. For example, an Oregon doctor stated that he declined a request for VAD from a diabetic patient who was refusing insulin treatment, but he would accept a request from a person with treatable lymphoma who was refusing chemotherapy.[119] The application of the statutory criteria may also vary according to the views of the assessing doctor, as other doctors have stated they would not accept a request from a person refusing lymphoma treatment.[120]

3 *Suffering*

[116] Ibid § 127.800(8).
[117] The Oregon Health Authority (unhelpfully) states that: 'The Act does not specify whether or not all treatment options must be exhausted prior to a prescription being written': Oregon Health Authority, 'Public Health's Role: Oregon's Death with Dignity Act', Government of Oregon (Web Page, 2020) <https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Pages/ohdrole.aspx>.
[118] Task Force to Improve the Care of Terminally-Ill Oregonians, Patrick Dunn and Bonnie Reagan (eds), *The Oregon Death With Dignity Act: A Guidebook for Health Care Professionals* (Centre for Ethics in Health Care, Oregon Health and Science University, 2007) Guideline 15.10 <https://www.wsha.org/wp-content/uploads/Death-with-Dignity_Death-with-dignity-guidebook.pdf>.
[119] Anita Hannig, 'Author(iz)ing Death: Medical Aid-in-Dying and the Morality of Suicide' (2019) 34(1) *Cultural Anthropology* 53, 70.
[120] Ibid.

There is no separate requirement under the Oregon Act that a person be in pain, or experiencing any suffering.[121] In this sense, the phrase 'suffering from a terminal illness' means having or experiencing such an illness.

4 *Voluntary*

To be eligible for VAD, a person must have 'voluntarily expressed his or her wish to die'.[122] The criteria for voluntariness are not defined in the Oregon Act, or in rules or regulations made under the Act.[123] However, witnesses are required to sign, as part of a person's request for assisted dying, that the person 'appears to be … not under duress, fraud or undue influence'.[124] It has been suggested that acting voluntarily involves excluding external influences such as duress, fraud or undue influence.[125]

[121] See Herbert Hendin and Kathleen Foley, 'Physician-Assisted Suicide in Oregon: A Medical Perspective' (2008) 106(8) *Michigan Law Review* 1613, 1615.
[122] *Oregon Act* (n 7) § 127.805.
[123] James Werth Jr and Howard Wineberg, 'A Critical Analysis of Criticisms of the Oregon Death With Dignity Act' (2004) 29(1) *Death Studies* 1, 20; Michaela Okninski, 'Commentary on Undue Influence Provisions under Oregon's Death with Dignity Act and California's End of Life Option Act' (2017) 25(1) *Journal of Law and Medicine* 77, 80. Clinical criteria to assess voluntariness have been proposed in David Orentlicher, Thaddeus M Pope and Ben A Rich, 'Clinical Criteria for Physician Assisted Aid in Dying' (2016) 19(3) *Journal of Palliative Medicine* 259.
[124] *Oregon Act* (n 7) § 127.897 ('Declaration of Witnesses Form').
[125] For this interpretation, see Okninski (n 123) 80. A witness' ability to attest to voluntariness has been questioned by Hendin, Foley and White who note that there is no requirement that the witnesses be independent of the person, or even that they know the person: Herbert Hendin, Kathleen Foley and Margot White, 'Physician-Assisted Suicide: Reflections on Oregon's First Case' (1998) 14(3) *Issues in Law & Medicine* 243, 255. Note also that Okninski has suggested that the Oregon Act does not provide sufficient protection against external factors which may overbear a person's will, because doctors are not required to report refusals of requests on the ground of concerns about voluntariness. This allows doctor shopping until a person or their relative finds a doctor willing to certify that a request for assistance to die is voluntary. Okninski cited anecdotal evidence of the Kate Cheney case, in which two doctors and a psychiatrist refused Ms Cheney's request because of concerns of undue influence or coercion by her daughter, before a doctor was found who was willing to write a prescription for lethal medication: Okninski (n 123) 82–3, citing Kathleen Foley and Herbert Hendin, 'Physician Assisted Suicide in Oregon: A Medical Perspective' (2008) 24(2) *Issues in Law and Medicine* 131, 131–2. We note, however, that the source of information about Kate Cheney for the Foley and Hendin paper is a 1999 newspaper article.

F *Canadian Criminal Code*

In February 2015, in *Carter v Canada (Attorney General)* ('*Carter*'),[126] the Supreme Court of Canada struck down the *Criminal Code* prohibition on voluntary euthanasia and assisted suicide, ruling it was contrary to the Canadian *Charter of Rights and Freedoms* ('the Charter'):

> The appropriate remedy is therefore a declaration that s. 241 (b) and s. 14 of the *Criminal Code* are void insofar as they prohibit physician-assisted death for a competent adult person who (1) clearly consents to the termination of life; and (2) has a grievous and irremediable medical condition (including an illness, disease or disability) that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition. 'Irremediable', it should be added, does not require the patient to undertake treatments that are not acceptable to the individual...[127]

In response to this decision, albeit after 16 months,[128] the Canadian Parliament passed *An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying)* in June 2016 ('Bill C-14').[129] This legislation permits 'medical assistance in dying' (MAiD), after a person seeking access for this assistance has been found to be eligible through a rigorous assessment process. MAiD includes both practitioner administration and self-administration, although, to date, self-administration has been very rarely used.[130]

[126] *Carter v Canada (Attorney General)* [2015] 1 SCR 331 ('*Carter*'). For commentary on this case, see Jocelyn Downie, 'Permitting Voluntary Euthanasia and Assisted Suicide: Law Reform Pathways for Common Law Jurisdictions' (2016) 16(1) *QUT Law Review* 84, 96–8.
[127] *Carter* (n 126) [127].
[128] The Court suspended the declaration of invalidity for 12 months to allow the Canadian government to develop a legislative response to the judgment: *Carter* (n 126) [147]. The suspension was then extended by a further four months due to a period of legislative inactivity because of an election: *Carter v Canada (Attorney General)* [2016] 1 SCR 13.
[129] Bill C-14 (n 27) amending the Canadian *Criminal Code* (n 9) ss 14, 226, 241. Although note that provincial legislation permitting VAD was first enacted in Quebec which commenced operation in December 2015: *An Act Respecting End-of-Life Care*, RSQ c S-32.0001.
[130] Christopher Harty et al, 'Oral Medical Assistance in Dying (MAiD): Informing Practice to Enhance Utilization In Canada' (2019) 66(9) *Canadian Journal of Anaesthesia* 1106.

For a person to be eligible for MAiD, Bill C-14 required that:

> 241.2(1)
>
> (a) they are eligible — or, but for any applicable minimum period of residence or waiting period, would be eligible — for health services funded by a government in Canada;
>
> (b) they are at least 18 years of age and capable of making decisions with respect to their health;
>
> (c) they have a grievous and irremediable medical condition;
>
> (d) they have made a voluntary request for medical assistance in dying that, in particular, was not made as a result of external pressure; and
>
> (e) they give informed consent to receive medical assistance in dying after having been informed of the means that are available to relieve their suffering, including palliative care.

Bill C-14 stated that a person has a grievous and irremediable medical condition if:

> (a) they have a serious and incurable illness, disease or disability;
>
> (b) they are in an advanced state of irreversible decline in capability;
>
> (c) that illness, disease or disability or that state of decline causes them enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable; and
>
> (d) their natural death has become reasonably foreseeable, taking into account all of their medical circumstances, without a prognosis necessarily having been made as to the specific length of time that they have remaining.[131]

Aspects of Bill C-14 were controversial from the outset, in particular the requirement that to amount to a grievous and irremediable medical condition a person's natural death must be

[131] Canadian *Criminal Code* (n 9) ss 241.2(2).

'reasonably foreseeable'.[132] Critics argued that this criterion violated the Charter, was too uncertain and was not an accurate reflection of the Supreme Court's reasoning in *Carter*.[133] On 11 September 2019, in *Truchon and Gladu v Canada (Attorney General)* ('*Truchon*'),[134] Baudouin J of the Quebec Superior Court accepted aspects of these arguments, and ruled that the 'reasonably foreseeable' eligibility criterion was constitutionally invalid.[135] In response to the *Truchon* decision, on March 17, 2021, Bill C-7 was passed and came into force. [136] Bill C-7 makes three changes to the law that are of particular relevance to this paper:

1. It repeals the eligibility criterion in s 241.2(2)(d) that a person's natural death must be reasonably foreseeable;

[132] 'Reasonably foreseeable' is not defined in the legislation. It is widely accepted that 'reasonably foreseeable' is not limited to situations in which: death is solely caused by the grievous and irremediable condition; death is imminent; the patient has a fatal condition; the patient is terminally ill; or the patient has an expected remaining lifespan of six months (as in Oregon, for example). See *AB v Canada (A-G)* [2017] ONSC 3759; Jocelyn Downie and Jennifer A Chandler, *Interpreting Canada's Medical Assistance in Dying Legislation* (IRPP Report, March 2018) <https://irpp.org/research-studies/interpreting-canadas-medical-assistance-in-dying-maid-legislation/> ('*IRPP Report*').

[133] See, eg, Jocelyn Downie and Kate Scallion, 'Foreseeably Unclear: The Meaning of the 'Reasonably Foreseeable' Criterion for Access to Medical Assistance in Dying in Canada' (2018) 41(1) *Dalhousie Law Journal* 23; James Downar and Louise Hugo Francescutti, 'Medical Assistance in Dying: Time for Physicians to Step Up and Protect Themselves and Patients' (2017) 189(25) *Canadian Medical Association Journal* E849. The primary source of uncertainty over 'reasonably foreseeable' death is how close to death a person must be to satisfy this requirement. On a narrow interpretation, a temporal link to death is required and that period of time must not be too remote, even though the medical or nurse practitioner does not have to estimate a specific length of time. On a broader interpretation, this criterion would be satisfied if *either* death is predicted in a period of time that is not too remote *or* there is a predictable cause of death. This latter interpretation is supported by, for example, College of Physicians and Surgeons of Nova Scotia, *Professional Standard Regarding Medical Assistance in Dying* (Professional Standard, 14 December 2018) <https://cpsns.ns.ca/wp-content/uploads/2018/12/ProfessionalStandard_MedicalAssistanceInDying_Dec2018.pdf>. In contrast, when introducing Bill C-7 (n 27) Justice Minister David Lametti appeared to endorse a narrower standard, although his office later clarified via email that the definition had not changed: Joan Bryden, 'Lametti Sows Uncertainty Over Meaning of Foreseeable Death in Assisted-Dying Bill', *National Newswatch* (online, 3 March 2020) <https://www.nationalnewswatch.com/2020/03/03/lametti-sows-uncertainty-over-meaning-of-foreseeable-death-in-assisted-dying-bill-2/#.Xl8BMkBuLvV>.

[134] *Truchon v Canada (A-G)* [2019] QCCS 3792 ('*Truchon*').

[135] Baudouin J suspended her declaration of invalidity for six months, giving the government until 11 March 2020 to amend the legislation (should it wish to do so). The government obtained four extensions of this deadline, and had had until 26 March 2021 to pass Bill C-7 (n 27). See Joan Bryden 'Feds get another month to reform assisted-dying law as bill stalls in the Commons' *CBC News* (online, 25 February 2021) < https://www.cbc.ca/news/politics/assisted-death-maid-1.5928316 >; *Truchon c. Procureur général du Canada* 2021 QCCS 590.

[136] Bill C-7 (n 27) came into force on 17 March 2021 <https://parl.ca/DocumentViewer/en/43-2/bill/C-7/royal-assent>.

2. It explicitly stipulates that (until 17 March 2023) for the purposes of determining whether someone has a serious and incurable illness, disease, or disability, mental illness is not considered an illness, disease, or disability;
3. It permits two forms of requests for MAiD made in advance of loss of decision-making capacity (a 'final consent waiver' and 'advance consent' explained in detail below).[137]

1 *Decision-Making Capacity*

The first eligibility criterion, in section 214.2(1)(a) of the Canadian Criminal Code, which we will not consider in detail, is that a person must be eligible for health services in Canada. The second criterion, in section 241.2(1)(b), is that a person accessing MAiD must be capable of making decisions with respect to their health. Two independent health practitioners must be of the opinion that this criterion and the other eligibility requirements are satisfied.[138] The capacity requirement is phrased more broadly in the Canadian *Criminal Code* than in the Australian models, which state that the person must have decision-making capacity for VAD specifically. In practice, however, capacity assessments are similar in Canada because it is understood that capacity in the health care context (and MAiD is understood to be a form of health care) is decision-specific.

The test for capacity is framed somewhat differently depending on the Canadian province or territory, but all provincial/territorial statutes centre on understanding the proposed treatment and appreciating the consequences of the decision.[139] Several provinces state that a person is

[137] Ibid s 241.2(3.2) ('final consent waiver') and (3.5) ('advance consent – self administration').
[138] Ibid ss 241.2(3)(a), (e), (f).
[139] See, eg, *Adult Guardianship and Trusteeship Act*, SA 2008, c A-4.2, s 1(d); *Health Care Consent and Care Facility (Admission) Act*, RSBC 1996, c 181, s 7; *Health Care Directives and Substitute Health Care Decision*

capable of making a treatment decision if they: 1) understand the information that is relevant to making the decision; and 2) appreciate the reasonably foreseeable consequences of both choosing the treatment and not choosing the treatment.[140] Other jurisdictions adopt additional,[141] or slightly different criteria.[142]

Canada is unique amongst the jurisdictions considered in this paper in permitting two limited forms of advance request for MAiD, through the 'final consent waiver' and 'advance consent – self-administration'. The default position in Canada is that a person must have capacity when making the request for MAiD and later when giving express consent immediately before it is provided.[143] However, this latter requirement can be waived for persons in two circumstances. First, for individuals whose natural death is reasonably foreseeable who have lost capacity after they have been found eligible for MAiD ('final consent waiver').[144] The final consent waiver is only valid if the person satisfies all eligibility criteria and safeguards in the legislation, and they have entered into a written agreement with a doctor or nurse practitioner to provide MAiD on a specified day.[145] The doctor or nurse practitioner must also have informed the person about the risk of losing capacity prior to the day specified.[146] If the person loses capacity, MAiD can be provided on or before the specified day. Despite this final consent waiver, the doctor or nurse practitioner must not administer the substance if the person resists or refuses by words, sounds

Makers Act, SS 2015, c H-0.002, s 2(1); *Health Care Directives Act*, CCSM 1993, c H27; *Health Care Consent Act*, SO 1996, c 2, s 4.

[140] *Adult Guardianship and Trusteeship Act*, SA 2008, c A-4.2, s 1(d); *Health Care Directives Act*, CCSM 1993, c H27, s 2; *Health Care Consent Act*, SO 1996 c 2, s 4.

[141] The Saskatchewan legislation adopts the two criteria used in Ontario, Alberta and Manitoba, and also requires that a person must be able to communicate a decision about the proposed treatment: *Health Care Directives and Substitute Health Care Decision Makers Act*, SS 2015, c H-0.002, s 2(1).

[142] In British Columbia, the *Health Care Consent and Care Facility (Admission) Act*, RSBC 1996, c 181, s 7 requires the health care provider to assess whether the adult demonstrates that they understand information about the proposed treatment.

[143] Canadian *Criminal Code* (n 9) ss 241.2(1)(b), (e), 241.2(3)(a), (h), 241.2(3.1)(a), (k).

[144] Canadian *Criminal Code* (n 9), s 241.2(3.2).

[145] Ibid s 241.2(3.2)(a)(i), (ii).

[146] Ibid s 241.2(3.2)(a)(iii).

or gestures.[147] Second, for persons (whether natural death is reasonably foreseeable or not), who enter into a written arrangement with their provider for MAiD to be provided should self-administration fail. In such circumstances, if the person has lost capacity, the practitioner was present at the time of self-administration, and the person has not died within the specified period has passed, the provider-administered MAiD is permitted.[148]

2 ***Grievous and Irremediable Medical Condition***

The most complex aspect of the eligibility criteria for MAiD is the requirement that the person have a grievous and irremediable medical condition. Section 241.2(2) of the *Criminal Code* states that a person will have a grievous and irremediable medical condition if:[149]

> (a) they have a serious and incurable illness, disease or disability;
>
> (b) they are in an advanced state of irreversible decline in capability; and
>
> (c) that illness, disease or disability or that state of decline causes them enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable.

(a) Serious and Incurable Illness, Disease or Disability

The first requirement for a 'grievous and irremediable medical condition' is that the person must have a serious and incurable illness, disease or disability.[150] A key issue is whether the medical condition must be incurable by any means, or whether it is limited to means that are

[147] Ibid s 241.2(3.2)(c). Note also that s 241.2(3.3), clarifies that 'involuntary words, sounds or gestures made in response to contact do not constitute a demonstration of refusal or resistance for the purposes of paragraph (3.2)(c)'.
[148] Ibid s 241.2(3.5).
[149] Canadian *Criminal Code* (n 9) s 241.2(2).
[150] Ibid s 241.2(2)(a).

acceptable to the patient.[151] Parliament did not define 'incurable' in the Criminal Code nor did the government define it in its Glossary to Bill C-14, and there is no case law on point. One interpretation is that 'incurable' should be viewed from an objective perspective because the government did not reference treatments acceptable to the person in the legislation, as it did in relation to the criterion of suffering.[152] The other interpretation, now widely accepted by MAiD assessors and providers' lawyers based on *Carter* and statements made in Parliament, is that incurable should be interpreted by reference to treatment that is acceptable to the person.[153]

Section 241.2(2.1) of the Canadian *Criminal Code* stipulates that a mental illness is not considered to be an illness, disease or disability under section 241.2(2)(a). This exclusion will be

[151] Note that this aspect of the Canadian *Criminal Code* (n 9) is one of the grounds for a 2016 constitutional challenge launched in *Lamb and British Columbia Civil Liberties Association v Canada (A-G)* [2016] Supreme Court of British Columbia, No S-165851 ('*Lamb*'); 'Notice of Civil Claim', *Lamb and British Columbia Civil Liberties Association v Canada (A-G)* (Supreme Court of British Columbia, No S-165851, 27 June 2016) <http://eol.law.dal.ca/wp-content/uploads/2016/07/Lamb-v-Canada.pdf> ('Lamb Claim') (now adjourned indefinitely. Lamb and the British Columbia Civil Liberties Association argued, in part, that the legislation is overbroad and violates the *Charter* (*Canada Act 1982* (UK) c 11, sch B pt I ('*Charter*')) for those individuals who have a grievous and irremediable medical condition that is curable (only by treatment options unacceptable to the patient). Note that the Attorney General in its Response to Civil Claim argued that the law does not infringe the *Charter* (or alternatively, if it does is a reasonable limit under section 1), but does not directly address the issue of treatments that are acceptable to the person: 'Response to Civil Claim', *Lamb and British Columbia Civil Liberties Association v Canada (A-G)* (Supreme Court of British Columbia, No S-165851, 27 July 2016) <https://bccla.org/wp-content/uploads/2016/08/2016-07-27-Response-to-Civil-Claim.pdf>.

[152] In other words, if the government had intended for 'incurable' to mean only by means that a person found acceptable, the government would have specified this in the provision itself: see discussion in *IRPP Report* (n 132) 16–19.

[153] Ibid. Downie and Chandler take the view that this criterion should be interpreted as 'in the professional opinion of the medical or nurse practitioner, the person cannot be cured by means acceptable to that person': at 17. In other words, a medical practitioner has concluded that there are no clinical options that would satisfy the individual's assessment of what is acceptable to them. Downie and Chandler raise a number of grounds for this including that such an approach is consistent with the position taken by the Supreme Court in *Carter* (n 126), and reflects the position taken by the Canadian Minister of Health and Senior Counsel for the Department of Justice when C-14 was before the Parliament: *IRPP Report* (n 132) at 18. Minister of Health and Department of Justice Senior Counsel both stated when appearing before the Senate that 'incurable' should be interpreted as including the phrase 'by any means acceptable to the patient': Canada, *Parliamentary Debates*, Senate, 1 June 2016, 1650 (Dr Jane Philpott) <www.parl.gc.ca/Content/Sen/Chamber/421/Debates/041db_2016-06-01-e.htm>; Evidence to Senate Standing Senate Committee on Legal and Constitutional Affairs, Parliament of Canada, Ottawa, 6 June 2016, (Bob Runciman, Chair) <www.parl.gc.ca/content/sen/committee/421/LCJC/52666-E.HTM>.

automatically repealed on 17 March 2023 by operation of a 'sunset clause' included in Bill C-7.[154]

(b) Advanced State of Irreversible Decline in Capability

A second requirement for a 'grievous and irremediable medical condition' is that the person must be 'in an advanced state of irreversible decline in capability'.[155] Again, there are no court decisions that consider the criterion,[156] and there are several aspects that are potentially unclear:[157] does the decline relate to cognitive as well as physical function; does it relate to stabilized as well as ongoing declines in capability? The latter uncertainty is significant, for example, to individuals who have had a precipitous decline in capability (such as from a previous traumatic injury) but who have stabilised. Downie and Chandler argue that such a person would satisfy the criterion,[158] although we note that this interpretation is somewhat broader than the wording in the Glossary that accompanied Bill C-14. The Glossary states that a person must be '*in* an irreversible decline towards death' [emphasis added], which could suggest that the decline needs to be ongoing. There is also uncertainty around the standard against which the decline is judged. Downie and Chandler argue that assessment should be relative to the individual's prior capability rather than some objective standard.[159]

[154] Bill C-7 (n 27) cl 6 specifies that the exclusion of mental illness as a sole underlying condition will be automatically repealed two years after Bill C-7 received royal assent, ie on 17 March 2023. This grace period is intended to enable the Government of Canada to commission an independent expert panel review of safeguards, protocols and guidance for MAiD and mental illness, and to allow the federal government and provincial and territorial governments enough time to develop these: Government of Canada, 'About Mental Illness and MAiD', *Medical Assistance in Dying* (webpage, 18 March 2021) <https://www.canada.ca/en/health-canada/services/medical-assistance-dying.html>.
[155] Canadian *Criminal Code* (n 9) s 241.2(2)(b).
[156] Note that one of the arguments in *Lamb* (n 151) (now adjourned indefinitely) was that the applicant is precluded from MAiD because she was not in an advanced state of irreversible decline, which she argued infringes her section 7 *Charter* (n 151) right to life, liberty and security of the person: Lamb Claim (n 151).
[157] See *IRPP Report* (n 132) 23–6.
[158] Ibid.
[159] Ibid.

(c) Intolerable Suffering

The third requirement of 'grievous and irremediable medical condition' is that *either* the illness, disease, disability *or* state of decline must be causing enduring physical or psychological suffering that is intolerable to the person.[160] The legislation frames this as a subjective inquiry; the provision refers to suffering that cannot be relieved under conditions the person considers acceptable.

3 ***Voluntary Request***

Like the model Bill and the WA Act, the Canadian *Criminal Code* includes a voluntary request as an eligibility criterion for MAiD. Section 241.2(1)(d) specifically notes that the request must not be made as a result of external pressure. A number of safeguards listed in section 241.2(3) and section 241.2(3.1) are designed to promote and ensure the voluntariness of the request.[161]

4 ***Informed Consent***

The final eligibility criterion is that the person must 'give informed consent to receive medical assistance in dying after having been informed of the means that are available to relieve their suffering, including palliative care' and, for persons whose natural death has not become reasonably foreseeable, have been 'informed of the means available to relieve their suffering, including, where appropriate, counselling services, mental health and disability support services, community services and palliative care.'[162] The legislation also requires that a person's

[160] Canadian *Criminal Code* (n 9) s 241.2(2)(c).
[161] The medical or nurse practitioner ('MAiD provider') must ensure the request is made in writing, signed and dated, and witnessed by one independent witness: Canadian *Criminal Code* (n 9) ss 241.2(3)(c), s 241.2(3.1)(c). The MAiD provider must also inform the person they may withdraw their request at any time and in any manner (ss 241.2(3)(d), 241.2(3.1)(d)), and must give the person an opportunity to withdraw the request immediately before providing MAiD (s 241(3.1)(k)) (except where the requirements for a final consent waiver or advance consent have been met under s 241.2(3.2) or (3.5) respectively).
[162] Ibid s 241.2(1)(e) and (3.1)(g).

request for MAiD must occur after they were informed by a medical or nurse practitioner that they have a grievous and irremediable medical condition.[163]

The federal *Criminal Code* requirement for informed consent intersects with provincial/territorial health care consent legislation[164] and the common law.[165] For example, for an adult to provide consent, British Columbia legislation imposes obligations on the health care provider to give the adult specified information including information about the person's condition, the nature of the proposed health care, the associated risks and benefits, alternative courses of health care, and the health care provider must give the adult an opportunity to ask questions and receive answers about the proposed health care.[166]

The common law has established that a health care provider seeking informed consent 'generally, should answer any specific questions posed by the patient as to the risks involved and should, without being questioned, disclose to him the nature of the proposed operation, its gravity, any material risks and any special or unusual risks attendant upon the performance of the operation.'[167]

Across Canada, the various laws taken together require the individual requesting MAiD to have any questions they ask answered by their health care provider and to be informed: that they

[163] Ibid s 241.2(3.1)(b)(ii).
[164] Consent to health care is a matter of provincial/territorial jurisdiction. See, eg, *Adult Guardianship and Trusteeship Act*, SA 2008, c A-4.2, s 1(d); *Health Care Consent and Care Facility (Admission) Act*, RSBC 1996, c 181, s 6; *The Health Care Directives and Substitute Health Care Decision Makers Act*, SS 2015, c H-0.002, s 2(1); *The Health Care Directives Act*, CCSM 1993, c H27; *Health Care Consent Act*, SO 1996, c 2, s 4.
[165] *Reibl v Hughes* [1980] 2 SCR 880. See College of Physicians and Surgeons of Alberta, *Informed Consent for Adults* (Advice to the Profession, August 2019) <http://www.cpsa.ca/wp-content/uploads/2016/02/AP_Informed-Consent-for-Adults.pdf>; College of Physicians and Surgeons of Alberta, *Informed Consent* (Standard of Practice, June 2016) <http://www.cpsa.ca/standardspractice/informed-consent/>. See also Louise Belanger-Hardy, 'Informed Choice in Medical Care' in Joanna Erdman, Vanessa Gruben and Erin Nelson (eds), *Canadian Health Law and Policy* (LexisNexis, 5th ed, 2017).
[166] *Health Care (Consent) and Care Facility (Admission) Act*, RSBC 1996, c 181, s 6.
[167] *Hopp v Lepp* [1980] 2 SCR 210.

have a grievous and irremediable medical condition; of the nature of MAiD; of material, special or unusual risks, and potential benefits of MAiD and other available treatment options (including no treatment); and of available means to relieve suffering, including palliative care.

III COMPARATIVE ANALYSIS OF KEY ELIGIBILITY CRITERIA RELATING TO A PERSON'S MEDICAL CONDITION

The purpose of this section is to undertake a comparative analysis of the eligibility criteria relevant to a person's medical condition and their access to VAD across the five models outlined above. The key criteria in this analysis are outlined below in Table 1, and the comparative issues that can have a significant impact on a person's access to VAD are explored below.

Table 1: Comparative Table of Key Criteria Relevant to Medical Conditions and Eligibility for Access to VAD[168]

CAPACITY					
	Victoria	**Model Bill**	**Western Australia**	**Oregon**	**Canada**
Nature of capacity[169]	decision-making capacity in relation to voluntary assisted dying	decision-making capacity in relation to voluntary assisted dying	decision-making capacity in relation to voluntary assisted dying	capable	capable of making decisions with respect to their health
NATURE OF MEDICAL CONDITION[170]					
	Victoria	**Model Bill**	**Western Australia**	**Oregon**	**Canada**
Prospect of cure	incurable	incurable	-	terminal disease, that is incurable and irreversible	incurable

[168] For ease of presentation, this table includes only the words in the various legislation and does not include a discussion of how particular concepts have been interpreted.
[169] For the purpose of this paper, the added complexity of whether capacity is assessed only at the time of a request for VAD, or also at the time of administration of VAD, is not separately considered.
[170] Although some jurisdictions use more precise terminology, such as 'disease, illness or medical condition' (*Victorian Act* (n 32) s 9(1)(d)), in this table the phrase 'medical condition' is employed for simplicity.

Stage and nature of condition	advanced and progressive	advanced and progressive	advanced and progressive	-	serious; advanced state of irreversible decline in capability
Prospect and timing of death	will cause death and this is expected within weeks or months, not exceeding six months or 12 months for neurodegenerative conditions	will cause death	will on balance of probabilities cause death within six months or 12 months for neurodegenerative conditions	will, within reasonable medical judgment, produce death within six months	
Specific statement about mental illness	mental illness alone is not eligible	-	mental illness alone is not eligible	ineligible if suffering from a psychiatric or psychological disorder or depression causing impaired judgment	mental illness is not an illness, disease or disability for the purpose of assessing the eligibility criteria
SUFFERING					
	Victoria	**Model Bill**	**Western Australia**	**Oregon**	**Canada**
Nature and source of suffering	medical condition is causing suffering to the person that cannot be relieved in a manner that the person considers tolerable	medical condition is causing intolerable and enduring suffering (subjective, includes suffering from treatment and can be physical, psychological and existential)	medical condition is causing suffering to the person that cannot be relieved in a manner that the person considers tolerable	-	medical condition or state of decline causes the person enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable

A *Prospect and Timing of Death*

There are two key points in relation to the prospect and timing of death required under the VAD models. First, as noted in Table 1, the time expected to death varies. Some models specify a time limit: six months in Oregon,[171] or six or 12 months depending on the medical condition in Victoria and Western Australia.[172] In contrast, the model Bill specifies no time limit or other temporal restriction on eligibility, but does require that a person has a condition that will cause death.[173] The broadest approach is the amended Canadian law. Canadian law does not require temporal proximity.[174] Although the operation in practice of these different legal approaches will be potentially qualified by interaction with other eligibility criteria, the criterion relating to prospect and timing of death plays a significant role in controlling access to VAD.

Second, there is also variability in wording about the level of certainty a doctor must have, or the 'standard of proof' that they must apply, in determining whether death will occur within that specified time. Formulations vary, with judgments about death to be made based on what is 'expected' (Victoria),[175] estimated to occur on 'the balance of probabilities' (Western Australia)[176] or assessed using 'reasonable medical judgment' (Oregon).[177] Of these three jurisdictions, perhaps most noteworthy is the Western Australian choice to use 'balance of probabilities'. This terminology was a considered departure from the Victorian drafting ('expected'), yet parliamentary debates suggest that the standard in Western Australia is not lower than under the Victorian Act.[178] Instead, the Western Australian Government considered that the 'balance of probabilities' test was adopted because it is easily understood by clinicians

[171] *Oregon Act* (n 7) § 127.800 § 1.01(12).
[172] *Victorian Act* (n 32) ss 9(1)(d)(iii), 9(4); *WA Act* (n 70) s 16(1)(c)(ii).
[173] Model Bill (n 22) cl 9(e)(i) simply states that the medical condition 'will cause the person's death'.
[174] Canadian *Criminal Code* (n 9) s 241.2(2).
[175] *Victorian Act* (n 32) s 9(1)(d)(iii).
[176] *WA Act* (n 70) s 16(1)(c)(ii).
[177] *Oregon Act* (n 7) § 127.800 § 1.01(12).
[178] Western Australia, *Parliamentary Debates*, Legislative Council, 26 Nov 2019, 9196 (Stephen Dawson).

and is a concept which 'provides the greatest clarity and most utility.'[179] All provide some discretion for doctors in determining prognosis, no doubt recognising the known difficulty of prognostication in relation to death. This was perhaps most explicitly recognised in the Canadian legislation between 2016 and 2021, which permitted a doctor to conclude that a person's death is reasonably foreseeable (an eligibility criterion at the time) 'without a prognosis necessarily having been made as to the specific length of time that they have remaining.'[180]

B *Suffering*

The models analysed also display significant variation in the level of suffering which must be experienced before a person is able to access VAD. There are three different thresholds of suffering across the five models of VAD. The first, the Oregon model, does not impose a suffering criterion (although the statute is worded to require a person to be 'suffering from a terminal disease').[181] Under the Victorian and Western Australian Acts, a person must be experiencing suffering, and this must not be able to 'be relieved in a manner that the person considers tolerable'.[182] The Canadian *Criminal Code* and the model Bill contain the highest threshold, requiring that a person be experiencing suffering that is 'intolerable' to them, is enduring, and (in Canada) that 'cannot be relieved under conditions that they consider acceptable'.[183]

Another key difference across models is the cause of the suffering. Under the Victorian and WA Acts, the terminal medical condition must be the cause of a person's suffering to be eligible for

[179] Ibid.
[180] Repealed by Bill C-7 (n 27) cl 1(1).]
[181] *Oregon Act* (n 7) § 127.805 § 2.01(1). Suffering here is used as meaning *having* a terminal illness.
[182] *Victorian Act* (n 32) s 9(1)(d)(iv); *WA Act* (n 70) s 16(1)(c)(iii).
[183] Canadian *Criminal Code* (n 9) s 241.2(2)(c); model Bill (n 22) cl 9(e)(i).

VAD.[184] The model Bill additionally recognises that the treatment for that condition may also be considered in assessing a person's suffering.[185] The Canadian approach is different again, as either the person's 'illness, disease or disability' or their 'state of decline' (that is, their advanced state of irreversible decline in capability) can be the cause of their suffering.[186]

Despite these differences, in the four models where suffering is required, there are also a number of similarities. One is that suffering is assessed subjectively by the person seeking VAD in all models.[187] This may mean that the differences in the suffering thresholds described above are less significant in practice if the requisite suffering is to be determined subjectively. Another is that suffering is broadly understood to encompass not only physical pain, but also psychological and existential suffering.[188]

C *Access to VAD and Mental Illness*

The VAD models differ in their treatment of the issue of mental illness. Four jurisdictions specifically address the impact of mental illness on possible access to VAD. The Victorian and WA Acts specifically state that mental illness on its own will not be sufficient to render a person eligible for VAD.[189] However, a person with a mental illness who also suffers from another medical condition that otherwise meets the criteria is still capable of qualifying under these models. The Canadian *Criminal Code* states (until the sunset clause takes effect on 17 March 2023) mental illness cannot be considered to be an illness, disease or disability for the purposes

[184] *Victorian Act* (n 32) s 9(1)(d)(iv); *WA Act* (n 70) s 16(1)(c)(iii).
[185] Model Bill (n 22) cl 10(2)(b).
[186] Canadian *Criminal Code* (n 9) s 241.2(2)(c).
[187] In Victoria and Western Australia, whether the suffering can be relieved in a manner that the person considers tolerable is subjectively assessed: *Victorian Act* (n 32) s 9(1)(d)(iv); *WA Act* (n 70) s 16(1)(c)(iii). Under the model Bill and in Canada, it is the suffering itself that is subjectively assessed by a person to be intolerable (as well as the proposed methods of relief, in Canada): model Bill (n 22) cl 10(2)(a); Canadian *Criminal Code* (n 9) s 241.2(2)(c).
[188] Canada includes 'physical or psychological suffering': Canadian *Criminal Code* (n 9) s 241.2(2)(c), whereas the model Bill includes 'physical, psychological and existential suffering': model Bill (n 22) cl 10(2)(c).
[189] *Victorian Act* (n 32) s 9(2); *WA Act* (n 70) s 16(2).

of assessing whether the patient has a serious and incurable illness, disease or disability. But, similar to the two Australian models, the Canadian law does not exclude access if mental illness is comorbid with another serious and incurable condition. The Oregon Act makes specific mention of mental illness, precluding access to VAD if a person is suffering from a psychological or psychiatric disorder or depression that causes impaired judgment. Once the person has been clinically assessed and determined not to have impaired judgment,[190] the person may access VAD if they have a terminal illness. Only the model Bill does not explicitly address mental illness. However, the way in which its other eligibility criteria are drawn makes it very unlikely that access only on the basis of mental illness would occur.[191]

D *Impact of Refusing Potentially Life-Sustaining Treatment*

A refusal of potentially life-sustaining treatment has relevance for two statutory criteria: an 'incurable' condition, and a condition that will 'cause death'. This issue is handled differently under the various models, and these differences are significant in terms of access to VAD. First, can a person be said to have an 'incurable' condition if they are refusing treatment that presents a reasonable prospect of a cure? The meaning of 'incurable' and the impact of treatment refusals is not explained in the legislation of the four jurisdictions which use this pivotal criterion.

In Victoria, extrinsic material states that whether a person's medical condition is incurable is a medical assessment based on available treatments and a person will not be eligible if they are

[190] *Oregon Act* (n 7) § 127.825.
[191] This is because in general mental illnesses are not terminal conditions. The majority of mental illnesses are cyclical, and do not progress naturally towards death. Note, however, the consideration of potential eligibility for access to VAD for anorexia, given that it is a mental illness which may be said in extreme cases to cause death: see White et al, 'Who is Eligible for VAD?' (n 20).

refusing treatment for an otherwise curable condition.[192] The model Bill uses the same language as the Victorian Act and would be interpreted in the same way. By contrast, in Canada, the practice appears to be that incurability is being determined having regard to treatments acceptable to the patient, although there are arguments that can be made to the contrary that treatment refusals should not be considered.[193] There is no available material to assist in the interpretation of this term in the Oregon Act.[194] Refusal of potentially life-sustaining treatment is a scenario which is likely to occur in practice. It would be desirable for legislation to give clear guidance to doctors about whether patients can make their condition incurable, and become eligible for VAD, through treatment refusal.

The impact of refusals of potentially life-sustaining treatment generally appears clearer in relation to the criterion of whether a medical condition will cause death, and within a certain period of time. In Victoria, extrinsic materials show that the requirement that a condition will cause death within six or 12 months will take account of the right to refuse treatments the person finds unacceptable.[195] Identical language is used in the WA Act, so that legislation is likely to be interpreted similarly. The model Bill makes this explicit with a provision clarifying that whether a medical condition will cause death 'is to be determined by reference to available medical treatment that is acceptable to the person'.[196] The Oregon Act, however, provides no guidance on this issue for courts or medical practitioners.

Significantly, in Western Australia, the government specifically chose not to include 'incurable' as a legislative criterion. This was because it was considered implicit in the criterion of a medical

[192] Explanatory Memorandum, VAD Bill (Vic) (n 46) cl 9. See discussion above Part II.B.2.
[193] See discussion above Part II.F.2.a.
[194] See discussion above Part II.E.2.
[195] Explanatory Memorandum, VAD Bill (Vic) (n 46) cl 9.
[196] Model Bill (n 22) cl 10(1).

condition which is advanced, progressive and will cause death. It was also considered inappropriate to require a person to exhaust all treatment options, when there is a long-established right to refuse treatment.[197] Although members of both Houses of Parliament sought to amend the VAD Bill (WA) to include 'incurable' as a criterion,[198] these amendments were rejected[199] and not included in the WA Act. Drawing on the analysis above, this means that in Western Australia, a person with a curable or treatable condition may be able to refuse treatment and become eligible to access VAD because they then (after treatment refusal) have a condition that will cause death. Examples given in parliamentary debates were an operable tumour[200] and gangrene which was curable with amputation.[201]

This is in contrast to the Victorian Act and the model Bill where incurability in the eligibility criteria functions as a limit on when access to VAD may be possible. Under those models, a person with a curable condition (such as an operable tumour or gangrene) will not be eligible for VAD, even if the person refuses the suggested treatment for that condition, because their condition will not be medically assessed to be 'incurable'. Some MPs in Western Australia have expressed concern that omitting incurability widens the category of people who may have access to VAD in that State.[202]

[197] Western Australia, *Parliamentary Debates*, Legislative Assembly, 5 September 2019, 6586 (Mark McGowan); Western Australia, *Parliamentary Debates*, Legislative Council, 26 November 2019, 9200 (Stephen Dawson).
[198] Western Australia, *Parliamentary Debates*, Legislative Assembly, 5 September 2019, 6601 (Margaret Quirk); Western Australia, *Parliamentary Debates,* Legislative Council, 26 November 2019, 9199 (Nick Goiran).
[199] Western Australia, *Parliamentary Debates*, Legislative Assembly, 5 September 2019, 6605; Western Australia, *Parliamentary Debates*, Legislative Council, 26 November 2019, 9202.
[200] Western Australia, *Parliamentary Debates*, Legislative Assembly, 5 September 2019, 6586 (Michael Nahan).
[201] Western Australia, *Parliamentary Debates*, Legislative Assembly, 5 September 2019, 6603–4 (Margaret Quirk); Western Australia *Parliamentary Debates*, Legislative Council, 26 November 2019, 9199 (Nick Goiran).
[202] See, eg, Western Australia, *Parliamentary Debates*, Legislative Assembly, 5 September 2019, 6602 (David Honey); Western Australia, *Parliamentary Debates*, Legislative Council, 26 November 2019, 9200 (Michael Mischin).

IV IMPLICATIONS OF COMPARATIVE ANALYSIS FOR DESIGN OF VAD REGULATION

The above analysis has demonstrated some important similarities and differences across five models of VAD laws. The purpose of eligibility criteria is to draw lines determining who should be able to access VAD. Within the five models considered, when analysing the criteria as a whole, it is apparent that these lines are drawn in quite different places. Canada has the most permissive eligibility criteria in its MAiD law, especially since Bill C-7 removed the reasonable foreseeability criterion introduced in Bill C-14. At the other end of the spectrum, the Victorian, WA and Oregon Acts are much more conservative.[203] This comparative analysis has important implications for the design of VAD regulatory systems more broadly. This section shifts beyond the specifics of these legal models and considers the wider questions they give rise to for policy-makers and legislators proposing laws in this area.

A *Challenge of Translating Policy Goals into Legislation*

One implication is the long-standing policy challenge of using words in legislation to reflect accurately a stated policy intent. The translation of broader social objectives into concrete legal rules is a challenging exercise.[204] Problems can arise not only in the selection of words, but also their interpretation, both by the courts and by those at the coalface who are charged with implementing the law. An ideal law is precise and can be applied consistently in relation to a wide variety of situations to which the law is intended to apply.[205] But legal rules are 'inherently

[203] This finding resonates with claims made by the Victorian Government at the time of the *Victorian Act* (n 32) passing: see Andrews Media Release (n 33).
[204] Karen Yeung, 'Regulating Assisted Dying' (2012) 23(2) *Kings Law Journal* 163, 168–70. See also White et al, 'Does the VAD Act (Vic) Reflect its Stated Policy Goals?' (n 58).
[205] Law Council of Australia, *Rule of Law Principles* (Policy Statement, March 2011) <https://www.lawcouncil.asn.au/lawcouncil/images/LCA-PDF/a-z-docs/PolicyStatementRuleofLaw.pdf>.

indeterminate', both because language is imprecise, and because they are subject to interpretation by others.[206]

Precision in wording can require compromises in terms of the congruence of the law with the policy goals underpinning it. An example of this is the imposition of a specified time limit to death in Victoria, Western Australia and Oregon.[207] An advantage of such an approach is it gives a concrete frame of reference for doctors and others to use when determining eligibility. (We put aside for the moment difficulties of prognostication.[208]) However, a precise time limit could be seen as an inadequate proxy for the wider policy intent: namely, identifying the cohort of people (those who are dying) for whom VAD should be made available. It can also operate arbitrarily, in that there may be very little to distinguish between a person who is expected to die within the specified time limit, and those with similar conditions whose prognosis is slightly longer. Rigidly applied, it also gives rise to injustices in some situations, such as where people are terminally ill and suffering, but are forced to continue to suffer until they are close enough to death to meet the eligibility time period.

An alternative is to use words that better reflect the policy intent but may be less precise. 'Natural death' being 'reasonably foreseeable' was an example of such an approach in Canada.[209] Although this drafting technique avoids the pitfalls of arbitrary time limits, it greatly increases the uncertainty surrounding the class of person to whom the legislation applies, as

[206] Yeung (n 204) 169. See also Julia Black, *Rules and Regulators* (Clarendon Press, 1997).
[207] In Victoria and Western Australia, a person must be suffering from a condition which is expected to cause death within six months, or 12 months if the condition is neurodegenerative: *Victorian Act* (n 32) ss 9(1)(d)(iii), 9(4); *WA Act* (n 70) s 16(1)(c)(ii). In Oregon, death must be anticipated within six months: *Oregon Act* (n 7) § 127.800 § 1.01(12). In contrast, the Canadian *Criminal Code* (n 9) includes no such time limit.
[208] Joanne Lynn et al, 'Defining the "Terminally Ill": Insights from SUPPORT' (1996) 35(1) *Duquesne Law Review* 311; Eric Chevlen, 'The Limits of Prognostication' (1996) 35(1) *Duquesne Law Review* 337; James Downar et al, 'The "Surprise Question" for Predicting Death in Seriously Ill Patients: A Systematic Review and Meta-Analysis' (2017) 189(13) *Canadian Medical Association Journal* E484; Paul Glare et al, 'Predicting Survival in Patients With Advanced Disease' (2008) 44(8) *European Journal of Cancer* 1146, 1147.
[209] Bill C-14 (n 27) s 241.2(2)(d), repealed by Bill C-7 (n 27) cl 1(1).

the extensive debate that has occurred in Canada about this terminology demonstrates. Such imprecision is problematic for doctors and others making assessments about eligibility for VAD.[210] This uncertainty can only be definitively resolved in an individual case through court decision, which is a costly and slow process, and judicial consideration of legislative terms can still fail to provide useful guidance in practice for other cases. Such uncertainty could, however, potentially be reduced through the use of other regulatory tools, such as guidelines or policy, to supplement law and provide greater clarity.

B *Operation of Eligibility Criteria is Shaped by Wider VAD System*

A second implication for VAD regulation is that the operation of eligibility criteria inevitably interacts with how the wider VAD system is designed. One illustration of this is the criterion of capacity. All models require that a person must have capacity at the point access to VAD is granted, and the concept of capacity is defined in broadly similar terms. However, differences in the way VAD is administered have significant effects on the timing of these capacity assessments, and thus on who may access VAD.

For Victoria, Western Australia and Oregon, capacity is required at the point of the final request for VAD. Where VAD occurs by self-administration, this means that capacity is last assessed when the person is approved to receive the VAD medication.[211] But this medication can be taken later, without medical or other supervision, and there is no testing of capacity at that point when the medication is actually taken. By contrast, where practitioner administration is

[210] Government of Victoria, Department of Health and Human Services, Ministerial Advisory Panel on Voluntary Assisted Dying, *Interim Report of the Ministerial Advisory Panel: Consultation Overview, Voluntary Assisted Dying Bill* (Interim Report, April 2017) 21–3.

[211] In terms of the final stage in the self-administration process where there is a legislative requirement to have capacity: in Victoria, this is the point at which the medical practitioner applies for a self-administration permit on behalf of a person: *Victorian Act* (n 32) s 47(3)(a). In Western Australia, this is at the point of final request: *WA Act* (n 70) s 51(3)(f)(i). In Oregon, this is immediately prior to writing a prescription: *Oregon Act* (n 7) § 127.830. See also the definition of 'qualified patient': *Oregon Act* (n 7) § 127.800 § 1.01(11).

authorised in Victoria and Western Australia, a person must have capacity at the time of administering the medication,[212] because the last request is made at the same time as VAD is administered.

For Canada, the position is similar to the extent that capacity must be assessed both when making a request for MAiD, and, with two exceptions, immediately before it is provided;[213] this latter point being at the time of administering the medication for practitioner administration and when prescribing or providing the medication for self-administration. However, if a person's death is reasonably foreseeable, there is an exception to this requirement of capacity at the time of MAiD provision if the conditions for a final consent waiver are met.[214] Whether a person's natural death is reasonably foreseeable or not, there is an also exception to the requirement of capacity at the time of MAiD provision for provider-administered MAiD where self-administration has failed and the conditions for an 'advance consent' are met. [215] Under the model Bill, capacity must be present during assessment and when VAD is provided.[216] VAD under this latter model, whether by self-administration or practitioner administration, is always medically supervised[217] and there is a final check of capacity at that point.[218] In short, although all models require a person to have capacity to request VAD, the overarching design of the VAD law results in this having different implications for those different models.

Another illustration is that there are sometimes fluid boundaries between whether a matter is stated to be a criterion of eligibility or a procedural step. It is possible conceptually for these

[212] *Victorian Act* (n 32) ss 64(1)(b), 65(2)(a)(i); *WA Act* (n 70) s 59(5)(a).
[213] Canadian *Criminal Code* (n 9) s 241.2(3)(a), referring to the eligibility criteria in s 241.2(1), including capacity in s 241.2(1)(b).
[214] Canadian *Criminal Code* (n 9) s 241.2(3.2) ('final consent waiver').
[215] Canadian *Criminal Code* (n 9) s 241.23.5 ('advance consent').
[216] Model Bill (n 22) cls 16, 21, 26(2), 29(1)(a)(ii), 29(2)(a)(iii), 30(1)(b), 32(2)(a).
[217] Ibid cl 6.
[218] Ibid cls 30(1)(b), 32(2)(a), 33(3).

parts of the legislation to be seen as distinct: one deals with the threshold question of access and the other relates to procedures that must be followed to receive access. However, these five models do reflect that some legislators have conceived certain aspects of their VAD law in different ways.

One example is the issue of 'informed consent'. This is stated to be part of the eligibility criteria in Canada, but not in the Australian models nor in Oregon. However, the need to provide information and ensure it is understood is an important part of the procedural steps outlined in these latter jurisdictions. Another example is that the requirement that a decision be made freely and voluntarily is a criterion of eligibility in the model Bill, the WA Act, the Canadian *Criminal Code* and the Oregon Act but in Victoria is tested at various points as a procedural issue. Thirdly, that the decision is enduring is a condition of eligibility in the model Bill and WA Act, but is tested through process in the other jurisdictions.

In practice, it may not be significant whether various issues are part of the threshold question of access or tested during various procedural steps. This may simply reflect a preference of legislators in terms of drafting or their understanding of how conceptually these matters contribute to the VAD system as safeguards. However, this distinction could potentially be significant, so reflection on whether a safeguard is better conceived as an eligibility criterion or process matter is important. For example, if the enduring nature of a person's request is imputed on the basis of them requesting VAD at three points in the process, this is different from requiring an enduring decision as a formal part of eligibility. A person could be prevaricating regularly over time and be regarded as not having made an enduring and settled decision to seek VAD, yet still have three points in time at which they were requesting it.

A final point to note about the operation of eligibility criteria is that it is shaped not only by the *design* of the wider VAD system, but it is also affected by how the system *functions in practice*. Thus, while a particular person may meet the legal eligibility criteria for VAD, their access to VAD depends upon a system that facilitates that, including access to willing doctors.[219]

C *Regulation Operates Holistically*

A third design point to make is that a system of regulation operates holistically. This means that looking at a single aspect of the eligibility criteria without understanding its role in the wider framework can be misleading. That is, it is important to examine eligibility criteria cumulatively and in context. This is the intention of the legislators in constructing the criteria in this way and this has significant implications for who can access VAD. As described above, the model Bill provides a good example of this: if the focus is restricted to the fact that the Bill does not impose a time limit until death, it may seem to be very broadly drafted. But when aggregated with the requirement for a medical condition that is incurable, advanced and progressive, the scope for access to VAD is considerably narrowed. This is not to make the case for wide or narrow criteria for access to VAD but to argue for a holistic assessment of cumulative eligibility criteria to properly represent the intent and scope of a VAD law.[220]

Taking a holistic view is also an important consideration more generally when designing VAD regulation. While it may be politically attractive to add numerous safeguards to VAD legislation, including in the eligibility criteria, there is a risk of what we have called elsewhere 'policy drift by a thousand cuts' if the cumulative effect of these individual safeguards is not properly

[219] We thank an anonymous reviewer for this point.
[220] This does not always happen: see, eg, comments of Archbishop Aspinall about the model Bill (n 22) which wrongly suggest it would permit persons with dementia to access VAD in Jamie Walker, 'Euthanasia Law A Life of its Own', *The Australian* (online, 31 August 2019).

considered.[221] For example, it is possible that a series of provisions designed to make VAD legislation safe, when aggregated, can in fact make access to VAD cumbersome or even unworkable.

V CONCLUSION

The purpose of eligibility criteria is to determine who will and will not be permitted to access VAD. As such, they play an important role in determining the scope of VAD laws, and are (rightly) heavily debated in parliaments considering reform. This paper has analysed the key eligibility criteria relevant to the medical condition of a person seeking access to VAD under five different legal models. Three of the models were Australian: the recently enacted legislation in Victoria and Western Australia along with a model Bill under consideration in Queensland. The remaining two VAD models analysed were from the common law jurisdictions of Oregon and Canada.

Comparative analysis is an established part of law reform processes[222] and so the evaluation undertaken above not only sheds light on how those laws should operate locally but also provides insights for other jurisdictions considering VAD reforms. Regulation permitting VAD remains relatively novel worldwide, so analysis of these individual models provides important insight for parliamentary committees, law reform bodies and parliamentarians. The paper has also considered what global lessons might be learned from how these five models operate. The preceding section considered important implications for designing VAD regulation generally, such as how eligibility criteria intersect with other parts of the VAD laws and the importance of evaluating criteria holistically to understand properly their legal effect.

[221] White et al, 'Does the VAD Act (Vic) Reflect its Stated Policy Goals?' (n 58).
[222] M van Hoecke, 'Methodology of Comparative Legal Research' (2015) *Law & Method* 1.

The analysis undertaken in this paper also provides a platform for the next paper in this series. Having explained and analysed the relevant legal criteria for accessing VAD in the five jurisdictions, the second paper will consider how these criteria will apply to specific medical conditions. What medical conditions might meet the criteria for access to VAD, and at what point in an illness trajectory will access be possible? This is different from the more conceptual and legal analysis already undertaken, but is critically important for optimal law reform. If parliamentarians intend to grant or deny access to VAD for particular medical conditions, then concrete testing of proposed eligibility criteria in relation to those conditions is essential.

4 Voluntary assisted dying in Victoria, Australia

A values-based critique

Lindy Willmott, Katrine Del Villar and Ben P. White

Introduction

In debates about whether voluntary assisted dying (VAD) should be legalised, we are all too familiar with the arguments for and against reform. Neither proponents nor opponents convince the other side of the legitimacy of their argument, nor expect to do so. Consensus is never reached. In this chapter, we offer an alternative lens through which to consider whether legislation should be enacted and, if so, the nature of that regulation. That lens is through an articulation and consideration of the values that we argue should underpin regulation of decision-making as individuals approach the end of their lives. While this approach will not result in others necessarily agreeing with our conclusions about whether or not VAD should be lawful, or the nature of any regulation, it does provide transparency and justification for our proposed stance.

We identify seven core values for this purpose: the importance of life, autonomy, freedom of conscience, equality, the rule of law, the protection of vulnerable people, and the minimisation of human suffering. These values are fundamental principles which are embedded in the Australian legal system, and are derived from case law and international human rights norms. They are protected by the common law and legislation across a range of legal areas, particularly the criminal law. To illustrate, the criminal law recognises the fundamental importance of human life by criminalising murder and assisting suicide. At the same time, our legal system also recognises the principle of autonomy by requiring doctors to comply with an advance directive that refuses life-sustaining treatment, even if that will result in a person's death. The other values are embedded in our legal systems in equivalent ways. Given the universality of these values, they would also resonate in other legal systems so may provide a useful framework for grappling with this issue in other jurisdictions.

In this chapter, we use this values-based approach to critique the *Voluntary Assisted Dying Act 2017* ('the VAD Act') which commenced operation in the Australian State of Victoria in June 2019. The VAD Act represents a very conservative, highly prescriptive model of VAD. It has been described by the

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Victorian Premier as the 'safest, and most conservative model in the world' (Andrews 2017).

The purpose of this chapter is to use our values framework to critique the VAD Act. The stated aim of the Victorian parliament was to design a legislative framework that is 'safe and compassionate' (Victorian Government 2017, 5). Its explicit aim was to balance respect for human life and the protection of vulnerable people against respect for the autonomous choices of those who are suffering from terminal conditions, and the compassionate alleviation of the suffering of those people (ibid., 44). However, in this chapter, we explore whether the legislation is successful in promoting these values, or whether amendments to the VAD Act are needed.

In the next section, we articulate the values that we argue should underpin legislation on this topic, and explain the implications of each value for the design of a legislative framework. The subsequent section then critiques the Victorian legislation against those values and conclusions are drawn about whether the legislation successfully promotes them.

Values that should underpin voluntary assisted dying law reform

As noted above, seven core values have been identified as relevant to developing and evaluating any model of access to VAD. These values are explored in more detail elsewhere (Willmott & White 2017), but each will be outlined briefly below.

The importance of life

The Australian legal system, like many other legal systems worldwide, recognises the fundamental importance of human life. The value of life is protected through the criminal law, which prohibits homicide in most circumstances, and makes assisting suicide unlawful. It is also explicitly recognised in common law cases on the withholding or withdrawal of potentially life-sustaining treatment.[1] However, the value of life is not absolute, and decisions can be made by or on behalf of a person to refuse life-sustaining medical treatment in certain circumstances (Willmott, White & Then 2018). For example, in some circumstances the burdens of treatment may outweigh the benefits so that treatment is not regarded as being in the person's best interests and can be withdrawn. This recognises that the value of human life is not unqualified, but may be outweighed in some circumstances by the disvalue of suffering.

In the context of VAD, it is commonly argued that the value of life can be protected through *prohibiting* VAD. However, it can also be argued that *permitting* VAD may advance the value of life. The Supreme Court of Canada in *Carter v Canada (Attorney General)* [2015] 1 SCR 331, paras. 57–58, noted that where ending one's own life is legally permitted but VAD is not, some individuals may feel constrained to end their life in advance of an anticipated

decline in physical capacity, to avoid being unable to legally choose to die at a later time when their condition has deteriorated. A legal system which allows for VAD under controlled circumstances would avoid this pre-emptive loss of life (see Chapter 6, this volume).

Autonomy

The principle of respect for autonomy is recognised as a fundamental value underpinning the Australian common law. This is reflected in its role as a core value in health law which upholds a competent individual's right to determine what treatment he or she receives or does not receive. The law prioritises autonomy over the State's interest in the value of life when a competent adult decides to refuse medical treatment.[2] However, in all states and territories in Australia the law currently prohibits a competent adult from exercising autonomy to seek assistance to end his or her life, except in the limited circumstances where VAD is now lawful in some states. In this respect, the law currently protects a narrow interpretation of autonomy as the 'right to prevent physical interference with one's bodily integrity' (Willmott & White 2017, 491), rather than a broader interpretation of autonomy as a right to self-determination (Skene 2004).

When considering laws relating to VAD, the principle of autonomy is frequently proffered to argue that the law should promote the broader value of autonomy as self-determination, that is, having one's will respected and acted on so that one could request assistance to die in certain circumstances. This reflects the contemporary Australian community's understanding of autonomy, and is consistent with the approach adopted by the Victorian Legislative Council Legal and Social Issues Committee when articulating the core values that they believed should underpin end-of-life care (LSIC 2016, xxi). It should be recognised, however, that like other values, respect for autonomy is not absolute and must be balanced against other competing values such as the importance of life. In other words, it would be justifiable to put some limits on the exercise of autonomy, for example by designing eligibility requirements to have access to assistance to die.

Freedom of conscience

Freedom of conscience is a freedom often combined with freedom of thought, religion and belief, and refers to the right not to be coerced or restrained in a way that limits that freedom.[3] It is a value derived from international human rights instruments (e.g. International Covenant on Civil and Political Rights, Article 18).[4] It is recognised explicitly in legislation in those Australian jurisdictions with domestic human rights laws. Australian law already respects the conscience of health professionals in relation to abortion by not requiring them to participate in termination procedures if that would be contrary to their conscience, and peak medical bodies endorse the ability of medical

practitioners and nurses to practise medicine in accordance with their conscientiously held beliefs (AMA 2019; ANMF 2015; MBA 2014).

The value of conscience suggests that health professionals should not be required to participate in VAD where doing so is contrary to their conscience. However, the right to act according to conscience is not absolute, and can be overridden where competing values require. For example, where a competent adult refuses potentially life-sustaining treatment, a medical practitioner must respect this choice notwithstanding his or her own conscientious beliefs. In the context of VAD, a health professional's right to freedom of conscience may conflict with an individual's right to access a lawful health service (VAD). Whether the Victorian legislation satisfactorily balances these competing interests is considered in more detail later in the article.

Equality

Equality is another core value of the Australian legal system. Unlike other Western countries, in Australia there is no general constitutional guarantee of equality, and the High Court has rejected attempts to imply it from the text and structure of the Constitution (Simpson 2018). However, the rule of law requires that the law treat people equally (Law Council of Australia 2011, 2). The *Convention on the Rights of Persons with Disabilities* (CRPD), which Australia has ratified, and human rights and anti-discrimination laws in the various Australian jurisdictions, all 'endorse equality and reject discrimination, including discrimination on the basis of disability' (Willmott & White 2017, 493). In Victoria, section 8(3) of the *Charter of Human Rights and Responsibilities Act 2006* (Vic) affirms that '[e]very person is equal before the law and is entitled to the equal protection of the law without discrimination …'.

Australian law adopts both formal and substantive concepts of equality, depending on the context. In the specific context of Victoria's *Charter of Human Rights and Responsibilities*, the value of 'equality before the law' has been held to require formal equality of treatment only.[5] By contrast, 'equal protection of the law without discrimination' imports substantive notions of equality: that is, equality of opportunity, including the adoption of positive measures to ameliorate conditions which may discriminate on the ground of disability.[6] The value of equality requires that laws conferring rights and duties should generally apply to all individuals, rather than privileging some and excluding others. Australian law does recognise, however, that some discrimination or differential treatment may be lawful when its purpose is to afford equal opportunity or equality of outcome to certain groups which have experienced disadvantage.[7] When critiquing VAD laws, the value of equality, in the sense of equal treatment and non-discrimination, must be considered in two respects. First, the mode of assisted death should not be limited to self-administration, because this would discriminate against those whose disability prevents them self-administering medication. Second, having a

disability should not of itself prevent a person from accessing VAD, if the person satisfies other legislative criteria.

Rule of law

The Australian legal system is built on the rule of law (Bailey 2009, 242–253; Toohey 1993, 168–169), a concept of ancient origin which incorporates fundamental principles such as the separation of powers, the equal application of laws, and procedural requirements such as access to a fair hearing (Bingham 2010; Tamanaha 2004, 33). Two important components of the rule of law are that the law must be 'certain and clear' and 'should be applied to all people equally and should not discriminate between people on arbitrary or irrational grounds' (Law Council of Australia 2011, 2).

In the context of VAD, the values of clarity and certainty require that any regulatory regime should have clearly expressed legal parameters so that health professionals and individuals wishing to access VAD can know how the regime applies and can act according to the law. In particular, offence provisions should be unambiguous, and key terms should be defined. There should also be certainty in the application of the law, which can be achieved through appropriate legislative safeguards to ensure that only those defined as eligible under the law have access to VAD, and robust oversight systems to ensure regulatory compliance with the scheme.

The second component of the rule of law – that 'law should be applied to all people equally and should not discriminate between people on arbitrary or irrational grounds' (Law Council of Australia 2011, 2) – is relevant to two aspects of VAD legislation. First, eligibility criteria to receive assistance under the legislation should have 'a demonstrable and rational basis' (Law Council of Australia 2011, 2) and should not arbitrarily or discriminatorily exclude a person or group of people. Second, safeguards and oversight mechanisms should be incorporated into the law to ensure that 'all people should be held to account for a breach of law, regardless of rank or station' (Law Council of Australia 2011, 2).

Protecting vulnerable people

Protecting vulnerable people within the community is at the heart of many branches of Anglo-Australian law (Herring 2016), including the law of torts (Stapleton 2003), equitable doctrines of undue influence and unconscionability (Hall 2012; Moore 2018), adult guardianship law (White, Willmott & Then 2018), and most especially criminal law (Lanham 2006). For example, Australian criminal law imposes duties on responsible caregivers to provide the 'necessaries of life' to vulnerable persons in their care (Willmott & White 2017, 496), and protects vulnerable people from being encouraged or coerced to take their own life by criminalising assisting a suicide (Otlowski 2000, 88).

Because this value is central to our legal system, it is essential that any legal response to VAD protects vulnerable people (LSIC 2017, xxi). But who is classified as vulnerable is a contested concept (Hall 2019, 7; Mayo & Gunderson 2002, 17–20), and may differ depending on the context. In the context of VAD, the Victorian Ministerial Advisory Panel on Voluntary Assisted Dying identified four specific groups of people as potentially vulnerable: the elderly, children, people with disabilities, and those with mental illness (Victorian Government 2017, 53–54, 82, 84, 88–90, 91). Other authors have eschewed any identification of certain 'populations' (Fineman 2008, 8) as inherently vulnerable, preferring instead situational or relational definitions of vulnerability (Brown, Ecclestone & Emmel 2017; Hall 2012, 31; Mackenzie, Rogers & Dodds 2014) or descriptions of universal vulnerability (Fineman 2008, 8).

In the context of VAD, every person seeking access to VAD may be described as situationally and relationally vulnerable by virtue of the fact that they are terminally or chronically ill, suffering and wishing to die. Therefore, it is undeniably important that the law provides safeguards to protect all people requesting VAD from the risk of coercion or undue influence arising from personal relationships or relationships with treating health professionals or care institutions. This can be achieved through eligibility criteria and procedural safeguards to ensure that a request for assistance to die is autonomous, voluntary and free from external pressure or coercion. It is also important that VAD laws do not exclude certain groups by labelling them as essentially or inherently 'vulnerable'. Care must be taken to ensure that people are not excluded from a system permitting VAD in a way which is discriminatory or disrespectful of their autonomous choices, simply because they fall within the category of those considered to be 'vulnerable' (Silvers 1998).

Reducing human suffering

A final value, found only in the end-of-life context rather than in the wider Australian legal system, is the value of reducing human suffering. This value is discerned chiefly from the common law doctrine of double effect. The doctrine of double effect legally protects a health professional who administers medication that may incidentally hasten death when a person is at the end of life and the professional's intention is to relieve pain and suffering rather than cause the person's death (White & Willmott 2018b). In this way, the law recognises that the value of life may be subordinated to the value of reducing human suffering in some circumstances. If VAD is legalised, this enables suffering to be addressed in a wider range of cases where an individual satisfies the eligibility requirements.

Critique of the Victorian legislation against the above values

Having identified and explained the values that we consider should guide law-making in the context of VAD, this section critiques the VAD Act against

these values. Given the word constraints of this chapter, we place particular emphasis on those parts of the Act where these values are not promoted.

Method of providing voluntary assisted dying

Overview of the law

The primary method of VAD permitted by the VAD Act is 'self-administration'. This involves a medical practitioner prescribing lethal medication which the patient then takes themselves (VAD Act, ss.45, 47). Administration of the medication by a practitioner (referred to in the Act as 'practitioner administration') is only authorised if the person seeking assistance to die has a disability which renders them 'physically incapable of the self-administration or digestion' of the medication (s.48(3)(a)). This narrow model of VAD contrasts with the majority of legislative models which were proposed but not enacted in Australia, which would have authorised the patient to choose the method of administration (Willmott et al. 2016, 27). Further, under the recently enacted *Voluntary Assisted Dying Act 2019* (WA) (s.56) and *End-of-Life Choices (Voluntary Assisted Dying) Act 2021* (Tas) (s.86(5)), greater choice is available to the patient to determine the method of administration.

Consistency with values

The Victorian decision to establish self-administration as the method of VAD except where this is a physical impossibility for the person appears to have been based primarily on the value of protecting vulnerable people. Deliberate self-administration of a lethal medication is a strong indication that a person's wish to die is autonomous, voluntary and enduring (Victorian Government 2017, 141). The inclusion of an exception, allowing practitioner administration where self-administration is not physically possible, ensures that the VAD Act does not discriminate on the basis of disability, which furthers the value of equality (p. 141).

However, the VAD Act restricts the choice of administration for the majority of people who are eligible and capable of self-administration, but have a preference for the medical practitioner to administer the lethal medication. If a person is physically able to swallow and ingest a lethal medication, the VAD Act does not allow for a practitioner to administer the medication. This restriction fails to respect the value of autonomy. Some people who are physically able to swallow and ingest a lethal medication may consider self-administration to be an unacceptable, or overly burdensome, option. In international jurisdictions where both methods are lawful, there is an overwhelming preference for practitioner administration over self-administration (Emanuel et al. 2016, 85). Further, some evidence suggests that the rate of complications and technical problems is twice as high when the lethal medication is self-administered, compared to when it is administered by a qualified medical practitioner (Groenewoud et al. 2000). Given these factors,

individual autonomy would be better respected by permitting all persons eligible for VAD to choose between self-administration or practitioner administration. Allowing individual choice between these methods would conform with models proposed in other Australian States, as well as international regimes such as Canada, the Netherlands, Belgium and Luxembourg (Emanuel et al. 2016, 79).

While self-administration as a default under the legislation may offer protection for vulnerable people by ensuring decisions to request VAD are voluntary and enduring, there are other ways to ensure these fundamental requirements are met. Limiting practitioner administration to those who are physically unable to administer the medication is inconsistent with the core value of respecting autonomy, by preventing people requesting VAD having access to choice as to the manner of their death, as well as prohibiting access to the safer option.

Eligibility

Overview of the law

There are five main eligibility requirements to receive VAD under the VAD Act: decision-making capacity; age; a terminal medical condition; suffering; and residency (VAD Act, s.9(1)). Access to VAD is limited to an adult who is an Australian citizen or permanent resident, and has been resident in Victoria for at least 12 months. The person must have an incurable disease, illness or medical condition that is advanced, progressive and is expected to cause death within six months (or 12 months in the case of a neurodegenerative condition [VAD Act, s.9(4)]), and is causing suffering that cannot be relieved in a manner that the person considers tolerable. The request for VAD must be made voluntarily and without coercion by a person who has decision-making capacity (VAD Act, s.9). Disability and mental illness alone are not grounds to request VAD, but a person with a disability or mental illness who is suffering from a terminal medical condition as described above and meets the other eligibility criteria is not precluded from accessing VAD.

Consistency with values

The VAD Act's eligibility criteria reflect a balancing of several of the core values: autonomy; the importance of life; reducing human suffering; and protecting vulnerable people. The decision to allow access to VAD advances the values of respecting autonomous choice and the compassionate alleviation of suffering. Further, the restriction of VAD to those with a terminal condition prioritises the values of respecting human life and safeguarding vulnerable people, by ensuring that only those who are already dying may request assistance to die. However, some of the eligibility requirements in the VAD Act (such as the inclusion of a temporal limit on eligibility for VAD and the

differential timeframe for neurodegenerative diseases [12 months] compared to other terminal conditions [six months]) have concerning implications for the values of equality and the rule of law.

CONSISTENCY WITH VALUES: DECISION-MAKING CAPACITY

The VAD Act is restricted to people with decision-making capacity. It does not permit decisions made by a substitute decision-maker, or decisions made in advance of anticipated loss of decision-making capacity via an advance directive, as occurs, although rarely, in the Netherlands and Belgium (Chambaere et al. 2015; Rurup et al. 2012). The capacity criterion promotes the value of autonomy, by ensuring that a request for assistance to die is made by a person with an ability to understand, retain and weigh that information in coming to their decision. This could also arguably provide a safeguard for vulnerable adults without decision-making capacity. The framework would not enable a substitute decision-maker to request assistance to die on their behalf.

CONSISTENCY WITH VALUES: AGE

The core value of autonomy is also consistent with the requirement that a person must be an adult to access VAD (Willmott & White 2017, 501). Adults are presumed to have decision-making capacity, and although minors may have capacity to make decisions concerning medical treatment including, in some cases, refusing life-sustaining medical treatment, they are often not considered to have sufficient maturity to make difficult decisions concerning death and dying (Victorian Government 2017, 54, 215). A prohibition on children accessing VAD is consistent with the Australian law which limits the ability of minors to request withdrawal of life-saving medical treatment in some cases, and with the consensus in the majority of overseas jurisdictions that access to VAD be limited to adults (Victorian Government 2017, 53). Only Belgium and the Netherlands permit requests for VAD to be made by children under the age of 18, and this occurs in practice only in very rare cases (CFCEE 2018, 11; Rietjens et al. 2014).

CONSISTENCY WITH VALUES: MEDICAL CONDITION

Three key values – the importance of life, autonomy and protecting vulnerable people – are engaged in determining what medical conditions meet the eligibility criteria for VAD. The VAD Act, like the majority of Australian Bills concerning VAD to date (Willmott et al. 2016, 34), and like VAD laws in US states, adopts narrow eligibility criteria, restricting access to VAD to people with a terminal illness, that is, people whose death is already inevitable and impending. The VAD Act also requires the disease that will cause that death to be incurable, advanced and progressive.

The requirement that the medical condition will cause the death of the patient recognises the intrinsic value of human life and constrains the values of autonomous choice and the alleviation of suffering, and the subjective value of life to the individual. It prevents people with unbearable suffering that they consider makes their life not worth living, but whose conditions are not progressively leading to death (or death within a specified timeframe), from exercising autonomous choices and seeking relief from their suffering through VAD. Some other jurisdictions such as Belgium and the Netherlands have chosen to resolve this tension more in favour of autonomous choice and the alleviation of suffering. These regimes allow individuals to access VAD if they suffer from a medical condition (in Belgium, the condition must be 'futile') which renders a person's quality of life intolerable for the person, even where the condition might not be terminal, and death not immediately foreseeable. Similar broader medical eligibility criteria have been proposed in several Australian Bills which failed to pass (Willmott et al. 2016, 34).

While the requirement that the medical condition causes the death of the person can be justified through a process of balancing relevant values (Willmott & White 2017, 502–503), particular problems arise by the inclusion of a temporal requirement that death is anticipated to occur within six months. Although this appears to respect the value of human life by restricting VAD to those already close to the end of life, there are significant difficulties accurately predicting when death is likely to occur, even in advanced terminal conditions (Chevlen 1996; Downar et al. 2017; Glare et al. 2008; Lynn et al. 1996). This means that some people whose death is imminent will be excluded by incorrect prognoses, thus failing to respect the core value of compassionate alleviation of suffering. In contrast, others who may have had years to live will be incorrectly predicted to die within six months (Lynn et al. 1996, 321–322), making them eligible for VAD, contrary to the policy goal of valuing human life. A temporal requirement that is unable to be estimated with precision will result in inconsistent application of the legislative criteria, 'with unjustified variations across diseases, across physicians, and across regions' (Lynn et al. 1996, 334). This results in uncertainty and arbitrariness in the application of the law, which is contrary to fundamental components of the rule of law.

Uniquely, the VAD Act contains two separate temporal limitations on eligibility – that death is expected within six months for most medical conditions, but is expected to occur within 12 months for people with neurodegenerative conditions. This differential timeframe has not been adequately explained by Parliament. It appears to have been motivated by a concern that people with neurodegenerative conditions might lose capacity and become ineligible to access VAD, although evidence supporting this was not provided. It is discriminatory and contrary to the value of equality to allow people with neurodegenerative conditions to access VAD earlier than people with other terminal conditions. It clearly values the lives of those with

neurodegenerative conditions differently than those with other conditions, as well as placing different value on the suffering experienced by each group. This distinction also infringes two foundational principles of the rule of law: namely, that laws apply equally to all, and that laws should not discriminate on 'arbitrary or irrational grounds' (Law Council of Australia 2011, 2).

CONSISTENCY WITH VALUES: NATURE OF SUFFERING

The VAD Act adopts a relatively broad approach in relation to suffering. First, it does not require physical pain, which some other Australian Bills have (Willmott et al. 2016, 35–36). Second, the Act makes clear that suffering is a subjective determination as to when it is not tolerable for the person based on the methods for alleviating suffering the person considers are acceptable. This promotes the twin values of reducing human suffering and respect for individual autonomy, by allowing the individual who is directly affected by the illness to determine the point at which the suffering outweighs the value of life for that individual (Willmott & White 2017, 504).

Safeguards

Overview of the law

The VAD Act contains numerous safeguards designed to ensure the accuracy of diagnosis and prognosis; and that patient requests for VAD are well-informed, competent and voluntary. The VAD Act prescribes a very detailed request and assessment process, requiring three separate requests by the person over a period of at least nine days (although this period can be reduced if the medical practitioners believe the person is likely to die during this period). One of these requests must be in writing, and signed by two independent witnesses who attest that the person is competent, acting voluntarily and understands the implications of their request (VAD Act, ss.34–36). Where VAD will be administered by a medical practitioner, the patient must make a fourth request immediately before administration to confirm the patient wants to proceed (s.64).

To be judged eligible to receive VAD, a person must undergo two independent medical assessments (VAD Act, Part 3, Divs 3 and 4) by suitably qualified and experienced medical practitioners (s 10). The medical assessments evaluate the person's diagnosis and prognosis, as well as capacity and voluntariness of the request for VAD (s.20(1)(b)). A medical practitioner must apply for and receive a permit from the relevant government department prior to VAD being provided (ss.47–48).

A unique feature of the legislation is that it specifically prohibits all registered health practitioners (including medical practitioners, nurses and allied health professionals) from directly or indirectly initiating a discussion about

VAD, or suggesting it as a treatment option (s.8). The legislation also contains numerous administrative safeguards, including detailed requirements to provide information to patients (ss.19, 28, 57, 58), designed to safeguard the autonomy and voluntariness of the patient's decision. There are also medication management procedures to protect the community by ensuring the secure storage and disposal of any lethal medication held by a patient at home (ss.61, 62). This safeguard is designed to ensure that the substance is used only by the person who has been assessed as eligible for VAD.

Consistency with values

Although the careful and prescriptive process for accessing VAD is designed to safeguard vulnerable people while respecting the autonomy of those with capacity to request assistance to die, there is a risk that the very detailed nature of these safeguards may compromise the VAD Act's ability to adequately promote autonomy, and may contribute to, rather than reduce, human suffering at the end of life, as is explained below.

CONSISTENCY WITH VALUES: REQUEST AND ASSESSMENT PROCESS

The multi-stage request and assessment process for VAD is designed to be rigorous in excluding those who are not eligible, and to ensure requests for VAD are voluntary decisions made by competent individuals. The requirement for at least one independent second medical opinion, confirming diagnosis, prognosis and capacity, is a feature common to all the Bills drafted in Australia and also international regimes. The need for repeated requests and other safeguards including the confirmation by (at least) a second medical practitioner arguably reaches a satisfactory balancing of values of the rule of law (compliance with the legislation) and promotion of autonomy (ensuring access by competent adults with an enduring request) with the value of life and protecting vulnerable people.

CONSISTENCY WITH VALUES: ENSURING THE REQUEST IS AN ENDURING ONE

An important safeguard in the VAD Act is a requirement that the request for assistance be an enduring one. One component of this safeguard is the need for a nine day period between the first and final request. A cooling off period of between 10 and 15 days is common in most international legislative regimes. Of note though is that this requirement, which is designed to foster autonomy, may paradoxically risk compromising this value, as there is a risk that the patient may lose capacity during this time (possibly because of pain-relieving medication), rendering the person ineligible for VAD (Downie 2017, 139; Willmott & White 2017, 507).

CONSISTENCY WITH VALUES: PROHIBITION ON INITIATING DISCUSSIONS

The prohibition on health practitioners initiating conversations about VAD is unique to Victoria. It is not a feature of any international legislative framework, and has been described as 'paternalistic' (Johnston & Cameron 2018, 456). The policy intent was to ensure that a 'person is not coerced or unduly influenced into accessing voluntary assisted dying and … the request for voluntary assisted dying is the person's own voluntary decision' (Victorian Government 2017, 91). However, preventing medical practitioners from raising VAD as a possible option (unless information about VAD is requested) compromises patients' ability to exercise fully autonomous choice between options available at the end of life (Willmott et al. 2020, 109). It may also obstruct the equal, non-discriminatory implementation of the VAD Act, by limiting access to more educated patients who are independently aware of their options, and excluding less informed patients who rely on their medical practitioners for information about treatment options (Johnston & Cameron 2018, 458–459).

Oversight

Overview of the law

The VAD Act contains a suite of mechanisms for monitoring the provision of VAD and ensuring compliance with the legislative regime. There are too many to consider in this chapter, so the focus here is on two main oversight mechanisms.

The first is the establishment of a new independent statutory body, the VAD Review Board ('Board') which has oversight of the scheme as a whole (VAD Act, s.92). The Board receives mandatory reports from medical practitioners and dispensing pharmacists at each step in the process of request and assessment of eligibility for VAD (ss.21, 30, 41, 49, 60, 63, 66). These reports enable the Board to ensure the legal requirements have been complied with in each individual case, and to evaluate overall patterns and trends in the administration of VAD, such as instances of 'doctor shopping' (Victorian Government 2017, 168).

The second oversight mechanism is the prior authorisation which must be obtained from the relevant government department before a medical practitioner can provide a patient with access to VAD. This application is made by the medical practitioner on completion of the required assessments, following the waiting period and after the third request from the patient.

Consistency with values

A rigorous oversight mechanism which ensures that the legislation operates as intended by parliament will promote all of the articulated values, but in

particular the rule of law. This is promoted by the Board having oversight over individual cases, and the system as a whole. Oversight also promotes the value of life and protecting vulnerable people by ensuring that only those who are eligible for VAD have access to it. Reporting all cases of VAD will safeguard the quality of the process (Smets et al. 2010), and therefore safeguard vulnerable individuals from abuse or coercion. Also, the value of autonomy is promoted by ensuring those who satisfy the eligibility requirements are able to have access to VAD.

The second main oversight mechanism, the requirement of pre-authorisation, is unusual internationally and warrants further examination. As this form of oversight occurs before VAD is administered, it is arguably a more effective safeguard for the value of human life than regimes which review processes after the death has occurred. However, this safeguard also requires more onerous processes and will delay a person's access to VAD, thereby potentially frustrating other values, such as autonomy and reducing human suffering. It is also unclear what degree of scrutiny will be undertaken by the government department before issuing a permit. The process itself may become a barrier to access, as medical practitioners may perceive the requirements to be unduly onerous or time-consuming. It must be questioned whether the processes and delay inherent in pre-authorisation, particularly if there is not detailed scrutiny of the individual case, achieve the correct balance between the competing values.

Role of conscience

Overview of the law

In Victoria, as in other jurisdictions, medical practitioners (and indeed all health practitioners) are not obliged to participate in VAD. Those who have a conscientious objection to assisting patients to die can choose not to be involved in the request and assessment process, in the administration of VAD or at any other stage (VAD Act, s.7). They are also not required by the VAD Act to refer the patient to another practitioner who does not hold a conscientious objection.

Consistency with values

The value of freedom of conscience is protected by the provisions in the VAD Act enabling health and medical practitioners to refuse to provide information about or participate in VAD. However, there being no duty on a conscientiously objecting practitioner to refer a patient may impede access to a lawful health service and so compromise respect for autonomous choices and compassion for intolerable suffering for some patients. There may also be issues with equality and discrimination, particularly for a patient living in a rural or remote area where the only available medical practitioner has a conscientious objection to participating in VAD. How the legislation is

implemented in practice will be critical to the VAD Act's ability to successfully balance these values.

Conclusion

Values held by individuals influence their views on what is right to do, or to allow to be done. In a similar way, parliamentarians who are charged with governing our countries support or oppose legislation on important social issues informed by their own set of values. This values-based exercise comes into sharp focus when members of parliament debate whether VAD should be permitted and, if it should be, the nature of the framework regulating its practice.

The values held by Victorian politicians led them to a collective decision to design a 'safe and compassionate' framework that permits and regulates VAD (Victorian Government 2017, 5). We would argue, however, that an appropriately drafted legislative regime should do more to promote the values articulated in this chapter, namely, the importance of life, autonomy, freedom of conscience, equality, the rule of law, the protection of vulnerable people, and the minimisation of human suffering.

As the critique in this chapter illustrates, the VAD Act promotes all of these core values, to varying degrees in different contexts. The enactment of legislation permitting VAD demonstrates respect for people's autonomous choices, and a desire to alleviate suffering at the end of life. However, in this chapter, we argue that future legislation should depart from the Victorian model in some significant ways to better promote the articulated values.

The dozens of unsuccessful attempts to pass legislation in Australian States and Territories over the past decades demonstrate the political challenges confronting parliaments that attempt reform in this field. The Victorian government is therefore to be commended for enacting legislation to permit VAD. However, as more jurisdictions in Australia and elsewhere consider reform (White & Willmott 2018a), we urge a shift in some critical aspects of the Victorian regulation, as articulated in this chapter, to better reflect the values that we consider should underpin such a regime.

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Legislation

Charter of Human Rights and Responsibilities Act 2006 (Vic).
Disability Discrimination Act 1992 (Cth).
End-of-Life Choices (Voluntary Assisted Dying) Act 2021 (Tas).
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Voluntary Assisted Dying Act 2019 (WA).
UN Convention on the Rights of Persons with Disabilities (CRPD).
UN International Covenant on Civil and Political Rights (ICCPR).

Cases

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Carter v Canada (Attorney General) [2015] 1 SCR 331.
Director of Public Transport v XFJ [2010] VSC 319.
H Ltd v Anor (2010) 107 SASR 352.
Hunter and New England Area Health Service v A (2009) 74 NSWLR 88.
Kuyken v Chief Commissioner of Police [2015] VSC 204.
Matsoukatidou v Yarra Ranges Council [2017] VSC 61.
Re JS [2014] NSWSC 302.

Notes

1 See, for example, *Brightwater Care Group (Inc) v Rossiter* (2009) 40 WAR 84 and *Hunter and New England Area Health Service v A* (2009) 74 NSWLR 88.
2 See, for example, *Brightwater Care Group (Inc) v Rossiter* (2009) 40 WAR 84, *H Ltd v Anor* (2010) 107 SASR 352 and *Re JS* [2014] NSWSC 302.
3 See, for example, *Charter of Human Rights and Responsibilities Act 2006* (Vic) s.14.
4 International Covenant on Civil and Political Rights, Article 18: (1) Everyone shall have the right to freedom of thought, conscience and religion. This right shall include freedom to have or to adopt a religion or belief of his choice, and freedom, either individually or in community with others and in public or private, to manifest his religion or belief in worship, observance, practice and teaching. (2) No one shall be subject to coercion which would impair his freedom to have or to adopt a religion or belief of his choice. (3) Freedom to manifest one's religion or beliefs may be subject only to such limitations as are prescribed by law and are necessary to protect public safety, order, health, or morals or the fundamental rights and freedoms of others. (4) The States Parties to the present Covenant undertake to have respect for the liberty of parents and, when applicable, legal guardians to ensure the religious and moral education of their children in conformity with their own convictions.
5 *Kuyken v Chief Commissioner of Police* [2015] VSC 204, [33] (Garde J); *Matsoukatidou v Yarra Ranges Council* [2017] VSC 61, [50] (Bell J).
6 *Matsoukatidou v Yarra Ranges Council* [2017] VSC 61, [50] (Bell J); *Director of Public Transport v XFJ* [2010] VSC 319.
7 For example, the *Charter of Human Rights and Responsibilities Act 2006* (Vic) s 8(4) states that 'measures taken for the purpose of assisting or advancing *persons* or groups of *persons* disadvantaged because of *discrimination* do not constitute *discrimination*'. See also *Disability Discrimination Act 1992* (Cth) s 45.

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Chapter 11

Voluntary Assisted Dying: Human Rights Implications for Australia

Lindy Willmott, Ben White and Katrine Del Villar*

INTRODUCTION

[11.10] Voluntary assisted dying (VAD) laws have been the subject of parliamentary debate for almost 30 years in Australia.[1] In 2017, Victoria became the first Australian jurisdiction in over 20 years to pass a VAD law.[2] This was followed by Western Australia in 2019.[3] Internationally, VAD is also gaining momentum. This is occurring mainly in Europe and North America. For example, in Europe, the Netherlands and Belgium passed VAD legislation in 2001 and 2002, respectively,[4] and Luxembourg followed in 2009.[5] In North

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1 This chapter uses the term voluntary assisted dying (VAD) as it is increasingly being adopted in Australia as the preferred term. VAD refers to a doctor taking active steps to end the life of a competent adult at their request (sometimes called voluntary euthanasia), and a doctor providing a competent adult with the means to end their own life, for example, by prescribing lethal medication (sometimes called physician-assisted suicide).

2 In 1995, the Northern Territory passed the first assisted dying legislation in the world: the *Rights of the Terminally Ill Act 1995* (NT). This was overturned by the federal government, which has constitutional power to pass laws for the territories in Australia: *Euthanasia Laws Act 1997* (Cth). See George Zdenkowski, Human Rights and Equal Opportunity Commission, *Human Rights and Euthanasia* (Occasional Paper, December 1996) 5-7.

3 For analysis of likely future reform in Australia, see Ben White and Lindy Willmott, 'Future of Assisted Dying Reform in Australia', (2018) 42 *Australian Health Review* 616. For a detailed analysis of the reform process in Victoria, see also Lindy Willmott and Ben White, 'The Challenging Path to Voluntary Assisted Dying Law Reform in Australia: Victoria as a Successful Case Study', in Ben White and Lindy Willmott (eds), *Politics, Persuasion and Persistence: International Perspectives on End-of-Life Law Reform* (Cambridge University Press, London, 2020) (forthcoming).

4 *Loi relative à l'euthanasie 2002* [*Act on Euthanasia 2002*] (Belgium); *Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding 2000* [*Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2000*] (Netherlands) [TR author].

5 *Loi du 16 mars 2009 sur l-euthanasie et l'assistance au suicide* [*Law of 16 March 2009 on Euthanasia and Assisted Suicide*] (Luxembourg) [TR author].

America, VAD is now lawful in nine states of the United States as well as in the District of Columbia,[6] and in 2016, VAD was legalised in Canada.[7]

While the drivers for reform have varied, human rights arguments have provided some of the impetus for legal change. This is notably the case in Canada, where the Supreme Court relied on the *Canadian Charter of Rights and Freedoms* (*Canadian Charter*) to conclude that a blanket prohibition on assisted suicide was unlawful. The decision resulted in the Canadian Government legalising 'medical aid in dying', as it is known in that country, in some circumstances. In other countries, efforts to use human rights to bring about reform have been less effective. Ongoing human rights litigation in the United Kingdom has been unsuccessful,[8] and a 2015 case in New Zealand also concluded that VAD cannot be justified on human rights grounds.[9]

This chapter begins by analysing the laws governing VAD in Australia, before considering VAD developments in three comparable jurisdictions, namely, Canada, the United Kingdom and New Zealand. All have human rights instruments and share a common law history, which makes them natural comparators for Australia. Jurisprudence from these three jurisdictions is frequently considered as authoritative or persuasive in Australia, particularly when it comes to issues about which Australian courts have not yet made determinations.[10]

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6 *Death with Dignity Act 1997*, Or Rev Stat §§ 127.800–127.995 (1994) (Oregon); *Death with Dignity Act*, Wash Rev Code §§ 70.245.010–70.245.904 (2008) (Washington); *Patient Choice and Control at End of Life Act*, Vt Stat Ann §§ 5281–93 (2013) (Vermont); *End of Life Option Act*, Cal Health and Safety Code §§ 443–443.22 (2015) (California); *Death with Dignity Act of 2016*, DC Code §7-661 (2017) (District of Columbia); *End-of-Life Options Act*, Colo Rev Stat § 25-48-101 (2017) (Colorado); *Our Care, Our Choice Act 2018*, HB 2739 (Hawaii); *Aid in Dying for the Terminally Ill Act*, S1072/A1504 (2019) (New Jersey); *An Act to Enact the Maine Death with Dignity Act*, 22 Me Rev Stat Ann §2140 (2019) (Maine). Assisted dying is also legal in Montana by virtue of the court ruling in *Baxter v Montana* 224 P 3d 1211 (MT, 2009).

7 *An Act to Amend the Criminal Code and to Make Related Amendments to Other Acts (Medical Assistance In Dying)*, SC 2016, c 3 (*Medical Assistance in Dying Act*). At the time of writing, a Bill to amend the *Criminal Code* has passed the first reading stage in the federal House of Commons and is in the midst of second reading debates: *Medical Assistance in Dying Act* (Bill C-7).

8 *Pretty v Director of Public Prosecutions and Secretary of State for the Home Department* [2002] 1 AC 800; *R (on the application of Nicklinson) v Ministry of Justice* [2015] AC 657; *R (on the application of Conway) v The Secretary of State for Justice* [2017] EWHC (Admin) 2447 [91]-[94] (Lord Sales LJ and Whipple and Garnham J); *R (on the application of Conway) v The Secretary of State for Justice* [2018] EWCA (Civ) 1431; *T v Secretary of State for Justice* [2017] EWHC (Admin) 3181; *R (On the Application Of T) v Ministry of Justice* [2018] EWHC (Admin) 2615.

9 *Seales v Attorney-General* [2015] 3 NZLR 556. An attempt to introduce VAD in New Zealand is now proceeding through legislative channels. The New Zealand Parliament passed its *End of Life Choice Act 2019* (NZ) in late 2019, however, this law will only take effect if approved by a public referendum.

10 The Australian High Court expressly acknowledged the desirability of obtaining guidance from the courts of the United Kingdom and other common law countries in *Cook v Cook* (1986) 162 CLR 376, 390 (Mason, Wilson, Deane and Dawson JJ). See also James Allsop, 'Some Reflections on the Sources of Our Law', (Conference Paper, Supreme Court of Western Australia Judges' Conference, 18 August 2012) 7-8.

Having outlined the key cases and findings from a human rights perspective, this chapter then considers the implications of this for Australia. It is noted that Australia differs from these other common law jurisdictions, in that human rights have had only a limited impact on debates concerning VAD. This is true even in Victoria, a state with a statutory Bill of rights and in which VAD was legalised.

The chapter concludes that human rights have a more limited influence on VAD law reform in Australia than in some other countries, because of the lack of a domestically enforceable human rights instrument at the national level and the limitations which exist at state and territory level. It is also concluded that although human rights are broadly expressed within VAD debates, they do not provide a single clear answer to the vexed moral question of whether assisted dying should be lawful; an issue on which the community is divided. Rather, it is the values and guiding principles enunciated by parliamentary committees of inquiry that have been more influential on legislative reform, in those Australian states which have enacted VAD laws.

LAW ON ASSISTED DYING IN AUSTRALIA

[11.20] Law reform in relation to assisted dying has been on the radar of the Commonwealth, as well as state and territory governments, for more than two decades. In 1995, the Northern Territory became the first jurisdiction in the world to briefly legalise VAD.[11] The law came into effect in 1996 but was overturned by the federal government in 1997.[12]

Despite extensive efforts to change the law (described briefly below), VAD remains unlawful in all Australian jurisdictions except Victoria and Western Australia. The criminal law regards ending another person's life as either murder or manslaughter.[13] Providing assistance to enable a person to end their own life is also a criminal offence and is generally described as aiding and abetting suicide.[14]

History of failed legislative attempts

[11.30] Although VAD law reform has been frequently placed on the political and legislative agenda, it has presented significant challenges. This is evidenced by the fact that, despite almost 60 Bills being introduced, only

11 *Rights of the Terminally Ill Act 1995* (NT).

12 The Commonwealth Government used its plenary constitutional power to pass laws that apply in the Territories pursuant to the *Commonwealth Constitution*, s 122. The Northern Territory and the Australian Capital Territory remain unable to pass any legislation authorising VAD until the Commonwealth Government lifts its prohibition on such laws: *Euthanasia Laws Act 1997* (Cth).

13 Lorana Bartels and Margaret Otlowski, 'A Right to Die? Euthanasia and the Law in Australia', (2010) 17 *Journal of Law and Medicine* 532, 533-535.

14 Ben White and Lindy Willmott, 'How Should Australia Regulate Voluntary Euthanasia and Assisted Suicide?', (2012) 20 *Journal of Law and Medicine* 410.

two have become law.[15] There have been more than 20 Bills introduced in South Australia alone, yet none were passed.[16] Since 2016, there has been increased legislative activity, and Bills have come close to being passed in South Australia[17] and New South Wales.[18] A Bill designed to restore the ability of the territories to legislate on VAD was also narrowly defeated in the federal Parliament.[19] In addition to this considerable legislative activity, governments in Victoria,[20] Western Australia,[21] Queensland[22] and the

15 A study of law reform efforts up to the end of 2015 documented 51 Bills, introduced at the Commonwealth, State and Territory level, 39 of which specifically aimed to legalise VAD: Lindy Willmott, Ben White, Christopher Stackpoole, Kelly Purser and Andrew McGee, '(Failed) Voluntary Euthanasia Law Reform in Australia: Two Decades of Trends, Models and Politics', (2016) 39(1) *University of New South Wales Law Journal* 1. A further eight Bills have been tabled between early 2016 and 2019: *Restoring Territory Rights (Dying with Dignity) Bill 2016* (Cth); *Death with Dignity Bill 2016* (SA); *Voluntary Euthanasia Bill 2016* (SA); *Voluntary Assisted Dying Bill 2016* (Tas); *Voluntary Assisted Dying Bill 2017* (Vic); *Voluntary Assisted Dying Bill 2017* (NSW); *Restoring Territory Rights Bill 2018* (Cth); and *Voluntary Assisted Dying Bill 2019* (WA). For more detail, see Lindy Willmott and Ben White, 'Assisted Dying in Australia: A Values-Based Model for Reform', in Ian Freckelton and Kerry Petersen (eds), *Tensions and Traumas in Health Law* (Federation Press, Sydney, 2017) 483-484, and White and Willmott, n 3.

16 Willmott et al, n 15, 16.

17 The *Death with Dignity Bill 2016* (SA) was defeated by one vote in the House of Assembly.

18 The *Voluntary Assisted Dying Bill 2017* (NSW) was also defeated by a single vote in the Legislative Council.

19 The *Restoring Territory Rights (Assisted Suicide Legislation) Bill 2015* was defeated in the Senate by two votes in August 2018.

20 Victoria pioneered this process, establishing a parliamentary committee of inquiry, whose report recommended the enactment of the *Voluntary Assisted Dying Act 2017* (Vic): Legal and Social Issues Committee, Parliament of Victoria Legislative Council, *Inquiry into End of Life Choices: Final Report* (Parliamentary Paper No 174, 9 June 2016). The Committee was followed by a multidisciplinary Ministerial Advisory Panel, comprised of experts in a number of fields, whose role was to advise as to the form of the legislation, taking into consideration a range of policy, clinical and legal issues: see Margaret O'Connor, Roger Hunt, Julian Gardner, Mary Draper, Ian Maddocks, Trish Malowney and Brian Owler, 'Documenting the Process of Developing the Victorian Voluntary Assisted Dying Legislation', (2018) 42 *Australian Health Review* 621, 625. For a detailed consideration of the reform process in Victoria, see Willmott and White, n 3.

21 A very similar process was adopted in Western Australia, where a parliamentary committee's report recommended the legalisation of VAD under certain circumstances: Joint Select Committee on End of Life Choices, Parliament of Western Australia, *My Life, My Choice* (First Report, 23 August 2018). This was followed with the establishment of a Ministerial Expert Panel, whose role was to assist in the consultation and development of legislation for VAD in Western Australia: Roger Cook, 'Government to Introduce Bill to Legalise Voluntary Assisted Dying and Improve End-of-Life Choices for Western Australians', (Media Statement, 12 November 2018). As was the case in Victoria, the legislation ultimately passed largely reflected the model proposed by the Ministerial Expert Panel.

22 In Queensland, the Government tasked the Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee of the Queensland Parliament with holding an inquiry into aged care, end-of-life and palliative care and voluntary assisted dying. This committee recommended reform and proposed a draft Bill for consideration: Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee, Parliament of Queensland, *Voluntary Assisted Dying* (Report No

ACT[23] have invested (or are currently investing) significant time and funding into conducting parliamentary reviews through the committee process.

VAD laws in Victoria and Western Australia

[11.40] The *Voluntary Assisted Dying Act 2017* (Vic) (the *VAD Act* (Vic)) commenced operation on 19 June 2019. Similar legislation – the *Voluntary Assisted Dying Act 2019* (WA) (the *VAD Act* (WA)) – was passed on 12 December 2019, and is expected to commence mid-2021. Under the *VAD Act* (Vic), health professionals are permitted to assist a terminally ill patient to die under strictly controlled circumstances. An individual can seek assistance to die only if they have an incurable disease, illness or medical condition that is advanced, progressive and is likely to result in death within six months (or 12 months, in the case of neurodegenerative conditions),[24] and which is causing suffering that cannot be relieved in a manner that the person considers tolerable.[25]

The default process under both Acts is 'self-administration'. For eligible people who are physically able to take and ingest the medication, a doctor will prescribe the medication which the person will ingest themselves.[26] Self-administration was considered to provide an important safeguard to ensure that a person's decision to die is truly voluntary and not coerced. In Victoria, when a person cannot physically take or digest the medication on their

34, 31 March 2020). The Queensland government responded to the committee's report by a referral to the Queensland Law Reform Commission, tasking the Commission to draft legislation for consideration by the Queensland Parliament. The terms of reference for the Commission are available at: https://www.qlrc.qld.gov.au/__data/assets/pdf_file/0004/651379/vad-tor.pdf.

23 In the ACT, a Select Committee on End of Life Choices inquired into VAD and other end of life issues, and issued its Report in March 2019: *Report from the Select Committee on End of Life Choices in the ACT* (Parliament of the Australian Capital Territory, 2019) 74-96.

24 *Voluntary Assisted Dying Act 2017* (Vic), s 9(1)(d). In the case of neurodegenerative conditions, death must be anticipated within the next 12 months: *Voluntary Assisted Dying Act 2017* (Vic), s 9(4). See also *Voluntary Assisted Dying Act 2019* (WA), s 16(1)(c), although there is no requirement that the disease be incurable in Western Australia.

25 *Voluntary Assisted Dying Act 2017* (Vic), s 9(1)(d)(iv) and *Voluntary Assisted Dying Act 2019* (WA), s 16(1)(c)(iii). There are also further eligibility requirements, which stipulate that individuals must be adults (*Voluntary Assisted Dying Act 2017* (Vic), s 9(1)(a); *Voluntary Assisted Dying Act 2019* (WA), s 16(1)(a)), an Australian citizen or permanent resident and resident in the State for at least 12 months (*Voluntary Assisted Dying Act 2017* (Vic), s 9(1)(b); *Voluntary Assisted Dying Act 2019* (WA), s 16(1)(b)), and have decision-making capacity in relation to a request for VAD (*Voluntary Assisted Dying Act 2017* (Vic), s 9(1)(c); *Voluntary Assisted Dying Act 2019* (WA), s 16(1)(d)). Decision-making capacity is defined in *Voluntary Assisted Dying Act 2017* (Vic), s 4 to mean understanding relevant information about the nature and effect of the decision; retaining that information; using or weighing that information as part of the decision-making process; and communicating the decision. A similar definition is contained in *Voluntary Assisted Dying Act 2019* (WA), s 6(2).

26 *Voluntary Assisted Dying Act 2017* (Vic), s 45. See also *Voluntary Assisted Dying Act 2019* (WA), s 56(1)(a).

own, a medical practitioner may administer it.[27] The criteria for practitioner administration are more flexible in Western Australia.[28]

The Victorian legislation has been described as the 'safest, and most conservative model in the world'.[29] The safeguards it contains include requiring repeated requests over at least a 10-day period before a person is considered to have formed an enduring desire to die,[30] and requiring two medical practitioners with a high level of training[31] and experience[32] to separately assess a person, both to confirm the diagnosis and prognosis of likely death within six months and to confirm that the person has formed a voluntary and competent wish for VAD.[33]

In Victoria, but not in Western Australia, VAD must be pre-authorised by the Secretary of the Department of Health by way of a 'voluntary assisted dying permit'.[34] There are also safeguards for the community, including having the lethal medication dispensed from a VAD statewide pharmacy as a single point of contact, requiring medication to be stored in a locked box[35] and requiring a contact person to be responsible for returning unused doses

27 *Voluntary Assisted Dying Act 2017* (Vic), s 46.

28 Practitioner administration is possible if self-administration is 'inappropriate', considering either the patient's ability to self-administer, the patient's concerns about self-administering the substance or the suitability of the method for administering the substance: *Voluntary Assisted Dying Act 2019* (WA), s 56(2).

29 Daniel Andrews, 'Voluntary Assisted Dying Model Established Ahead of Vote in Parliament', (Media Release, Victorian Government, 25 July 2017).

30 The process involves an initial (usually oral) request for assisted dying, two separate assessments of eligibility (including capacity), a written declaration of intent and a final request, which must usually be made at least nine days after the initial request: *Voluntary Assisted Dying Act 2017* (Vic), Pt 3. See also *Voluntary Assisted Dying Act 2019* (WA), Pt 3.

31 Both the coordinating medical practitioner and the consulting medical practitioner must complete 'approved assessment training': *Voluntary Assisted Dying Act 2017* (Vic), ss 19, 26, 114. See also *Voluntary Assisted Dying Act 2019* (WA), ss 25, 36.

32 Both the coordinating medical practitioner and the consulting medical practitioner must be a fellow with a specialist medical college or be a vocationally registered general practitioner. One of them must have practised for at least five years after completing the fellowship or vocational registration. And one must have relevant expertise and experience in the patient's disease, illness or medical condition: *Voluntary Assisted Dying Act 2017* (Vic), s 10. In Western Australia, both the coordinating and consulting medical practitioners must hold either specialist registration for at least one year, or general registration for at least 10 years, or be an overseas trained specialist who meets additional requirements approved by the Chief Executive Officer of the relevant Government Department. There is no requirement for expertise in the patient's particular condition: *Voluntary Assisted Dying Act 2019* (WA), s 17.

33 *Voluntary Assisted Dying Act 2017* (Vic), ss 16, 25; *Voluntary Assisted Dying Act 2019* (WA), ss 24, 35.

34 *Voluntary Assisted Dying Act 2017* (Vic), ss 47-48.

35 *Voluntary Assisted Dying Act 2017* (Vic), s 61. This requirement is not contained in the *VAD Act* (WA).

or leftover medication.[36] Finally, medical practitioners have no obligation to be involved in the scheme.[37] They may refuse a request for assisted dying on the grounds of a conscientious objection, and in Western Australia only, a clinician who refuses a first request must advise the patient immediately and also provide the patient with prescribed information.[38]

THE HUMAN RIGHTS CASE FOR REFORM

[11.50] While the pathway to reform in Australia has been through legislation, attempts to reform the law in the United Kingdom, Canada and New Zealand have occurred through litigation. Individuals have brought court cases challenging prohibitions on VAD on the grounds that such prohibitions breach their human rights. The applicants in the proceedings have argued that the blanket criminal prohibitions on assisting another person to suicide (and in some cases, on mercy killing[39] or voluntary euthanasia[40]), violate the right to die or the right to assisted suicide.[41] This 'right' has been described variously as the 'right to commit suicide',[42] the 'right to die',[43] the 'right to die with dignity',[44] the 'right to choose how or when to

36 The substance must be returned within 15 days of the date of death, or if a person decides not to proceed with self-administration, when the person requests it to be returned: *Voluntary Assisted Dying Act 2017* (Vic), ss 39, 89. The period is 14 days in Western Australia: *Voluntary Assisted Dying Act 2019* (WA), s 105.

37 *Voluntary Assisted Dying Act 2017* (Vic), s 7; *Voluntary Assisted Dying Act 2019* (WA), s 9(1).

38 *Voluntary Assisted Dying Act 2017* (Vic), ss 13(1)(b)(i), 23(1)(b); *Voluntary Assisted Dying Act 2019* (WA), s 20(5).

39 Mercy killing is an informal term used in some cases to describe 'an intentional killing which is prima facie murder but which is carried out for compassionate motives, often by a member of the family or a friend of the victim': Margaret Otlowski, 'Mercy Killing Cases in the Australian Criminal Justice System', (1993) 17 *Criminal Law Journal* 10, 10; and Katrine Del Villar, Lindy Willmott and Ben White, 'Suicides, Assisted Suicides and "Mercy Killings": Would Voluntary Assisted Dying Prevent These "Bad Deaths"?', (2020) *Monash University Law Review* (forthcoming). It involves active steps to cause death, which distinguishes it from self-administration under the VAD regime. Further, it may occur at the request of, or without a request from, the deceased person, so unlike VAD may not always be voluntary.

40 Voluntary euthanasia refers to the deliberate act of one person to end the life of another to relieve that person's suffering, where the person wishing to die is competent and has requested to die. Practitioner administration under the VAD regime is an example of voluntary euthanasia.

41 *R (on the application of Nicklinson) v Ministry of Justice* [2015] AC 657; *Carter v Canada (A-G)* [2015] 1 SCR 331; *Seales v Attorney-General* [2015] 3 NZLR 556.

42 Lord Wilson spoke of a 'positive legal *right* to commit suicide' in *Nicklinson* [200]; whereas Lord Sumption stated that although suicide is not a crime, 'there is no right to commit suicide': *R (on the application of Nicklinson) v Ministry of Justice* [2015] AC 657 [211]-[213].

43 *Pretty v Director of Public Prosecutions and Secretary of State for the Home Department* [2002] 1 AC 800 [4] (Lord Bingham CJ).

44 This was claimed by Mrs Rodriguez in *Rodriguez v British Columbia (A-G)* [1993] 3 SCR 519, 532. Cory J in dissent accepted that the right to life includes a right to die with dignity on the ground that 'dying is an integral part of living': at 630.

die'[45] and the 'right to choose death rather than life'.[46] More emotively, it has also been described as 'the right to avoid a distressing and undignified end to life'[47] or the 'right to bring intolerable suffering to an end'.[48]

The applicants in these cases have argued that the criminal prohibition breaches national or regional Bills of rights,[49] which often replicate rights contained in the International Bill of Rights.[50] International human rights instruments are founded on core concepts of human dignity, liberty and equality.[51] They contain a number of relevant rights which may potentially be engaged in arguing for reform of the law relating to assistance in dying.[52] Chief among these are the rights to life,[53] liberty and security of the person,[54] privacy[55] and equality.[56]

Considering whether a prohibition on VAD infringes human rights requires a three-step analysis. First, it is necessary to *define the scope* of the right in issue. Second, it is necessary to consider whether a particular right is *engaged* (ie, the right itself has been infringed or breached, or the freedom to exercise the right has been restricted).[57] For example, a person's right to life

45 *Pretty v Director of Public Prosecutions and Secretary of State for the Home Department* [2002] 1 AC 800 [87] (Lord Hope), [18] (Lord Bingham CJ). This was formulated as the 'right to have control over the timing, method and circumstances of one's death' by Mrs Rodriguez in *Rodriguez v British Columbia (A-G)* [1993] 3 SCR 519, 532.

46 *Pretty v Director of Public Prosecutions and Secretary of State for the Home Department* [2002] 1 AC 800.

47 *R (on the application of Nicklinson) v Ministry of Justice* [2015] AC 657 [29] (Lord Neuberger).

48 *R (on the application of Nicklinson) v Ministry of Justice* [2015] AC 657 [336] (Lord Kerr).

49 In Canada, these rights are contained in the *Canada Act 1982* (UK), c 11, Sch B Pt I (*Canadian Charter of Rights and Freedoms*); in New Zealand, they are in the *New Zealand Bill of Rights Act 1990* (NZ); and in England, in the *European Convention on Human Rights*, reproduced in the *Human Rights Act 1998* (UK).

50 *Universal Declaration of Human Rights*, GA Res 217A (III), UN GAOR, UN Doc A/810 (10 December 1948); *International Covenant on Civil and Political Rights*, opened for signature 16 December 1966, 999 UNTS 171 (entered into force 23 March 1976); *International Covenant on Economic, Social and Cultural Rights*, opened for signature 16 December 1966, 993 UNTS 3 (entered into force 3 January 1976).

51 The first sentence of the *Universal Declaration of Human Rights*, Art 1 declares: 'All human beings are born free and equal in dignity and rights'.

52 Many of these rights are also enshrined in regional and national human rights laws.

53 *International Covenant on Civil and Political Rights*, Art 6(1).

54 *Universal Declaration of Human Rights*, Art 3; *International Covenant on Civil and Political Rights*, Art 9.

55 *International Covenant on Civil and Political Rights*, Art 17; *Universal Declaration of Human Rights*, Art 12.

56 *International Covenant on Civil and Political Rights*, Art 26; *Universal Declaration of Human Rights*, Art 7. The right to health contained in *International Covenant on Economic, Social and Cultural Rights*, Art 12 also includes the right to control one's own health and body, but has not been emphasised in case law to date asserting a right to assistance in dying.

57 See, for example, in relation to whether the prohibition on assisted suicide engaged any of Mrs Pretty's rights under the *Convention for the Protection of Human Rights and Fundamental Freedoms*, opened for signature 4 November 1950, 213 UNTS 221 (entered into force 3

is engaged where an action directly causes death, thus depriving a person of life. Similarly, a person's right to liberty is engaged where the freedom to act in a particular way is restricted. Third, if a human right is engaged, it is necessary to consider whether the restriction or interference with the right is *justified*, by reference to some overarching societal objective.[58] For example, it is legitimate to kill an enemy combatant in time of war, even though this violates their right to life.

In deciding human rights cases, courts apply this approach, which recognises that human rights are not absolute. Some rights are subject to limitations contained within the text of the right itself, which may permit derogations that are 'necessary in a democratic society',[59] or are in accordance with 'principles of fundamental justice'.[60] And many Bills of rights contain a general limitation provision making the enjoyment of human rights subject to 'such reasonable limits prescribed by law as can be demonstrably justified in a free and democratic society'.[61]

The evaluation of when a restriction of human rights is demonstrably justified is a question on which reasonable minds can, and frequently do, differ. Courts around the world vary in their interpretation of what is a legitimate social purpose, and in their assessment of which restrictions are necessary and justified to achieve that purpose. For example, when deliberating on VAD cases, the Canadian Supreme Court in *Carter v Canada (Attorney General)*[62] (*Carter*) and the New Zealand High Court in *Seales v Attorney-General*[63] (*Seales*) considered similar arguments concerning deprivation of the right to life and restriction of the right to liberty (or privacy, in New Zealand, which incorporates liberty interests). However, in Canada, the Supreme Court unanimously concluded that the restriction of human rights

September 1953); Antje Pedain, 'The Human Rights Dimension of the *Diane Pretty* Case', (2003) 62(1) *Cambridge Law Journal* 181, 184-192.

58 Pedain, n 57, 192-203. Stevie Martin uses the terminology of 'an interference' to describe when a human right has been engaged, and a 'violation' to designate an interference without legitimate justification: Stevie Martin, 'A Human Rights Perspective of Assisted Suicide: Accounting for Disparate Jurisprudence', (2018) 26(1) *Medical Law Review* 98.

59 Several articles of the *Convention for the Protection of Human Rights and Fundamental Freedoms*, including the right to respect for one's private life (Art 8), contain the qualification that restrictions may be justified if they are 'in accordance with the law' and are 'necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others'.

60 The right to life, liberty and security in *Canadian Charter of Rights and Freedoms*, s 7, and the right to life in the *New Zealand Bill of Rights Act 1990* (NZ), s 8 are both expressed to be subject to restrictions which are 'in accordance with the principles of fundamental justice'.

61 *Canadian Charter of Rights and Freedoms*, s 1; *New Zealand Bill of Rights Act 1990* (NZ), s 5; *Charter of Rights and Responsibilities Act 2006* (Vic), s 7(2) (*Victorian Charter*); *Human Rights Act 2004* (ACT), s 28(1). See also Denise Meyerson, 'Why Courts Should Not Balance Rights against the Public Interest', (2007) 31 *Melbourne University Law Review* 873, 876-877.

62 *Carter v Canada (Attorney General)* [2015] 1 SCR 331.

63 *Seales v Attorney-General* [2015] 3 NZLR 556.

was not demonstrably necessary and that there should be provision for VAD with appropriate safeguards to protect the interests of vulnerable people. By contrast, in New Zealand, the High Court accepted that the prohibition on assisted suicide was justified, and therefore held that there had been no breach of human rights.

In some cases, opinions differ even among judges within the same court as to whether particular restrictions are justified or infringe human rights.[64] The following sections briefly analyse the four human rights which have been argued to be engaged by a prohibition of VAD. This is followed by a discussion of when limitations on these rights might be justified.[65]

Right to life

[11.60] The right to life is 'the first substantive right' in many international treaties, which 'reflects its fundamental importance'.[66] The United Nations (UN) Human Rights Committee has described it as: 'the supreme right from which no derogation is permitted'.[67] Article 6(1) of the *International Covenant on Civil and Political Rights* (ICCPR) states: 'Every human being has the inherent right to life. This right shall be protected by law. No one shall be arbitrarily deprived of his life'.[68] Although most cases and commentary on the right to life have been concerned with lethal force, the death penalty and unlawful violence,[69] the Human Rights Committee did briefly address the issue of assisted dying in General Comment 36, in 2018. It neither expressed a view that the right to life required states to provide assisted dying, nor did it suggest that the right to life would be infringed by laws permitting assisted dying. It simply stated:[70]

> States parties that allow medical professionals to provide medical treatment or the medical means to facilitate the termination of life of afflicted adults, such as the terminally ill, who experience severe physical or mental pain and suffering and wish to die with dignity, must ensure the existence of robust legal and

64 See, for example, *Rodriguez*, where the Supreme Court of Canada split 5:4, and *Nicklinson*, where the nine-member bench of the UK Supreme Court was divided along a number of lines.

65 For a useful discussion of which international human rights might be engaged in the context of voluntary assisted dying, see also Australian Human Rights Commission, *Euthanasia, Human Rights and the Law* (Issues Paper, May 2016) and Martin, n 58.

66 Ilias Bantekas and Lutz Oette, *International Human Rights: Law and Practice* (2nd ed, Cambridge University Press, Cambridge, 2016) 342.

67 Human Rights Committee, *General Comment 36: Article 6: The Right to Life*, UN Doc CCPR/C/GC/36 (30 October 2018) [2].

68 See also *Convention for the Protection of Human Rights and Fundamental Freedoms*, Art 2; *Convention on the Rights of the Child*, opened for signature 20 November 1999, UNTS 1577 (entered into force 2 September 1990), Art 6; *Convention on the Rights of Persons with Disabilities* (A/RES/61/106), opened for signature 30 March 2007 (entered into force 3 May 2008), Art 10.

69 See Bantekas and Oette, n 66, 342-349.

70 Human Rights Committee, n 67, [9].

> institutional safeguards to verify that medical professionals are complying with the free, informed, explicit and unambiguous decision of their patients, with a view to protecting patients from pressure and abuse.

In the common law cases, two principal arguments have been made concerning the right to life. First, it has been argued that the right to life encompasses the full spectrum of living, including death and dying. Accordingly, the argument is that the right to life includes a right to die or to make autonomous choices concerning death.[71] Comparison is often made to current legal principles authorising the withholding and withdrawal of life-saving medical treatment, even from an incompetent patient, and the administration of palliative medication, which may also have the effect of potentially hastening death. The European Court of Human Rights (ECtHR) considered the application of the right to life[72] in the context of a woman with motor neurone disease who challenged the prohibition on assisted suicide. In *Pretty v United Kingdom* (*Pretty*), the ECtHR rejected an argument that the right to life includes a right to die, or a right to self-determination, which allows a person to choose death rather than life.[73]

Second, it has been argued that the right to life is concerned not just with 'the fact of life, but also with the quality and dignity of life',[74] and that notions of human dignity require that a person has the ability to choose to end their life when it has lost its meaning or all sense of purpose or pleasure.[75] Neither of these arguments have been accepted by courts anywhere in the world.[76]

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71 This was the argument of Mrs Pretty in *Pretty v Director of Public Prosecutions and Secretary of State for the Home Department* [2002] 1 AC 800 [4] (Lord Bingham CJ). It was also accepted by two dissenting judges (of different appellate courts) in the Canadian case of *Rodriguez*: *Rodriguez v British Columbia (A-G)* (1993) 76 BCLR (2d) 145 [158] (McEachern J dissenting); *Rodriguez v British Columbia (A-G)* [1993] 3 SCR 519, 630 (Cory J dissenting). See also Elizabeth Wicks, 'The Law and Ethics of Assisted Dying: Is There a Right to Die?', in Elizabeth Wicks (ed), *Human Rights and Healthcare* (Hart Publishing, London, 2007) 259-261.

72 *Convention for the Protection of Human Rights and Fundamental Freedoms*, Art 2 is the equivalent of the ICCPR, Art 6.

73 *Pretty v United Kingdom* (2002) 35 EHRR 1.

74 This argument was accepted by some dissenting judges of the British Columbia Court of Appeal in Canada: *Rodriguez v British Columbia (A-G)* (1993) 76 BCLR (2d) 145 [158] (McEachern J dissenting); *Carter v Canada* [2013] 51 BCLR (5th) 213 [84]-[89] (Finch CJ dissenting). It was not accepted by the unanimous Canadian Supreme Court in *Carter v Canada (A-G)* [2015] 1 SCR 331. See also Wicks, n 71, 261-264.

75 This argument was mentioned in *Rodriguez v British Columbia (A-G)* [1993] 3 SCR 519, 630 (Cory J dissenting). Arguments concerning the scope and application of the right to life have also been considered in depth in Danuta Mendelson and Mirko Bagaric, 'Assisted Suicide through the Prism of the Right to Life', (2013) 36 *International Journal of Law and Psychiatry* 406 and Zdenkowski, n 2, 5-7.

76 *Carter v Canada (A-G)* [2015] 1 SCR 331 [59]-[62]; *Pretty v Director of Public Prosecutions and Secretary of State for the Home Department* [2002] 1 AC 800 [4] (Lord Bingham CJ), [87] (Lord Hope); *Seales v Attorney-General* [2015] 3 NZLR 556; *Fleming v Ireland* [2013] IESC 19; *Washington v Glucksburg*, 521 US 702 (1997); *Vacco v Quill*, 521 US 793 (1997). This argument was accepted by Fabricius J at first instance in *Stransham-Ford v Minister of Justice and Correctional Services* [2015] 3 All SA 109 [12] (High Court). However, the South African

More recently, a third argument involving the right to life has been advanced. It was accepted in both the Canadian case of *Carter* and the New Zealand case of *Seales* that prohibiting assistance in dying is a denial of the right to life for some people with progressive and degenerative disabilities, because it forces them to commit suicide prematurely, while they still retain the physical ability to do so without assistance, due to the knowledge that the option of assistance will be lawfully unavailable to them at a later time when their condition has deteriorated.[77] There is evidence that this does occur in a percentage of suicides every year.[78]

Right to liberty and security of the person

[11.70] The right to liberty and security is found in Art 9 of the ICCPR,[79] and provides that:

> Everyone has the right to liberty and security of person. No one shall be subjected to arbitrary arrest or detention. No one shall be deprived of his liberty except on such grounds and in accordance with such procedure as are established by law.

The Human Rights Committee has stated that: '[l]iberty of person concerns freedom from confinement of the body, not a general freedom of action'. It defined 'security of the person' similarly, as concerning 'freedom from injury to the body and the mind, or bodily and mental integrity'.[80] The international jurisprudence on this right has focused on coercive action such as arrest, detention, deprivation of liberty and the preventative detention of asylum seekers and refugees.[81] It has not been concerned with autonomy generally, or freedom to make decisions concerning the end of one's life.

In contrast to the narrow interpretation of the right to liberty internationally, in Canada, the right to liberty contained in the *Canadian Charter* has been more broadly interpreted. In that country, it includes the right to be free from governmental interference in making fundamental personal decisions,

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Supreme Court of Appeal posthumously allowed an appeal against this judgment, and was critical of Fabricius J for determining issues which were unnecessary to decide, without having fully heard argument. It also referred to local and international authority suggesting that the right to life did not include a right to choose when to die: *Minister of Justice and Correctional Services v Estate Stransham-Ford* [2017] 1 All SA 354 [63] (Supreme Court of Appeal).

77 See *Seales v Attorney-General* [2015] 3 NZLR 556 [29]; *Carter v Canada (Attorney General)* [2012] BCSC 886 [1322]; *Carter v Canada (A-G)* [2015] 1 SCR 331 [57]-[58].

78 *Seales v Attorney-General* [2015] 3 NZLR 556 [51]-[52]; *R (on the application of Nicklinson) v Ministry of Justice* [2015] AC 657 (Lord Neuberger).

79 It is also found in other international instruments, such as the *Convention on the Rights of the Child*, Art 37, *Convention on the Rights of Persons with Disabilities*, Art 14, *Convention for the Protection of Human Rights and Fundamental Freedoms*, Art 5.

80 Human Rights Committee, *General Comment 35: Article 9 (Liberty and Security of Person)* UN Doc CCPR/C/GC/35 (16 December 2014) [3].

81 A useful collection of this jurisprudence is contained in Human Rights Committee, n 80. See also Bantekas and Oette, n 66, 368-375.

including decisions concerning medical treatment.[82] Similarly, the right to security of the person embraces personal autonomy, including the right to freedom from State interference in matters concerning one's body. The Supreme Court of Canada accepted that both the rights to liberty and security of the person are engaged by laws criminalising assistance in dying,[83] because the prohibition interferes with 'fundamental personal choices' concerning medical care. The Supreme Court viewed VAD as one of a range of available options together with palliative medication, withholding or withdrawing life-sustaining treatment, including the withdrawal of artificial nutrition and hydration.[84]

The right to liberty and security of the person has not been specifically considered in cases in New Zealand or the United Kingdom. The *New Zealand Bill of Rights Act 1990* (NZ) does not contain an analogous right,[85] and the right to liberty and security was not argued in the UK cases.[86]

Right to respect for private life

[11.80] The right to privacy contained in Art 17 of the ICCPR provides that: '[n]o one shall be subjected to arbitrary or unlawful interference with his privacy, family, home or correspondence, nor to unlawful attacks on his honour and reputation'.[87] Although the UN Human Rights Committee has not defined 'privacy',[88] it clearly encompasses activities related to the disclosure, collection and storage of personal information and records. In addition, in *Toonen v Australia*, the Committee stated that laws that criminalised homosexual conduct between consenting adults in private violated the right to privacy.[89] Accordingly, this right is broad enough to include a right to freedom from unwarranted and unreasonable intrusions into activities that society recognises as falling within the private sphere of individual autonomy.

82 See *Carter v Canada (Attorney General)* [2012] BCSC 886 [1302]; *Carter v Canada (A-G)* [2015] 1 SCR 331 [64].

83 *Rodriguez v British Columbia (A-G)* [1993] 3 SCR 519, 583; *Carter v Canada (A-G)* [2015] 1 SCR 331.

84 See *Carter v Canada (A-G)* [2015] 1 SCR 331 [66].

85 The right to 'liberty of the person' is specifically confined to freedom from arbitrary arrest and detention: *New Zealand Bill of Rights Act 1990* (NZ), s 22.

86 The *Convention for the Protection of Human Rights and Fundamental Freedoms*, Art 5, which contains the right to liberty and security of the person, has not been argued to be engaged in any of the English cases. An equivalent right was raised in South Africa in the case of *Stransham-Ford v Minister of Justice and Correctional Services* [2015] 3 All SA 109 (High Court). The liberty interest protected by the due process clause of the 14th amendment was also invoked in *Washington v Glucksburg* 521 US 702 (1997).

87 See also *Convention for the Protection of Human Rights and Fundamental Freedoms*, Art 8; *Convention on the Rights of the Child*, Art 16; *Convention on the Rights of Persons with Disabilities*, Art 22.

88 Nor has it issued a General Comment setting out its interpretation of Art 17.

89 *Toonen v Australia*, Human Rights Committee Communication No 488/1992.

In several European cases, the ECtHR has specifically considered whether laws prohibiting assisting suicide (in the Kingdom[90] and Germany[91]) and allowing assisted suicide subject to certain conditions (in Switzerland[92]) violate an individual's right to privacy. The Court held that the right to privacy in Art 8 of the *European Convention on Human Rights* (ECHR) includes the right to determine the timing and manner of one's death.[93] However, the Court also found that the relevant laws fall within the wide 'margin of appreciation' afforded to individual countries. Although some cases found there had been procedural violations of the right to privacy,[94] no case found that a prohibition on assisted dying, or the imposition of conditions, breached the right.

Like the European cases, the right which has been the main focus of the English cases has been the right to respect for one's private life.[95] This right, like the Canadian right to liberty and security of the person, protects autonomy and self-determination. It requires non-interference by the State in matters of personal choice and has been argued to protect the right to choose the time and manner of one's death. In *Pretty*, the House of Lords held that the right protected only 'personal autonomy while individuals are living their lives', rather than autonomy in choosing not to live any longer.[96] However, it is now well established that the right to respect for one's private life encompasses the right to choose the time and manner of one's death.[97]

As previously noted, human rights are not absolute, but are subject to such limitations as are justified and necessary. To date, the English courts have held that although a person's right to privacy is engaged by a criminal

90 *Pretty v United Kingdom* (2002) 35 EHRR 1; *Nicklinson and Lamb v United Kingdom* [2015] ECHR 709.

91 *Koch v Germany* (2013) 56 EHRR 6.

92 *Haas v Switzerland* (2011) 53 EHRR 33; *Gross v Switzerland* (2014) 58 EHRR 7.

93 *Koch v Germany* (2013) 56 EHRR 6.

94 In *Koch*, it was held that the failure by German courts to consider the merits of a claim under Art 8 was a breach of Art 8: *Koch v Germany* (2013) 56 EHRR 6. In *Gross*, the requirement to have a prescription to access lethal medication was not considered a violation of Art 8, but the lack of clarity in the Swiss law around the circumstances in which a prescription could be obtained was: *Gross v Switzerland* (2014) 58 EHRR 7. It is worth noting that the issue in that case was moot, as Ms Gross had already received assistance in dying but had taken special measures to conceal this fact from the ECtHR, so that her claim would not be discontinued. As such, the findings in *Gross* are not legally valid: European Court of Human Rights, *End of Life and the European Convention on Human Rights. Factsheet* (January 2018) 3.

95 Contained in the *Convention for the Protection of Human Rights and Fundamental Freedoms*, Art 8, and reproduced in the *Human Rights Act 1998* (UK).

96 *Pretty v Director of Public Prosecutions and Secretary of State for the Home Department* [2002] 1 AC 800 [23] (Lord Bingham CJ), [61] (Lord Steyn J).

97 *R (on the application of Nicklinson) v Ministry of Justice* [2015] AC 657 [29] (Lord Neuberger, quoting *Haas v Switzerland* (2011) 53 EHRR 33 [51], *Koch v Germany* (2013) 56 EHRR 6 [46], [51] and *Gross v Switzerland* (2014) 58 EHRR 7 [60]). See also *R (on the application of Conway) v The Secretary of State for Justice* [2018] EWCA (Civ) 1431 [11].

prohibition on assisted suicide, this restriction is justified as necessary to protect vulnerable people in the community, and accordingly, does not infringe the right to privacy.[98]

Right to equality

[11.90] The final human right which is potentially relevant to cases of assisted dying is the right to equality or freedom from discrimination. Article 26[99] of the ICCPR states: '[a]ll persons are equal before the law and are entitled without any discrimination to the equal protection of the law'.[100] This article prohibits discrimination under law and enshrines a 'basic and general principle' that the law should treat all persons equally.[101] However, the Human Rights Committee has recognised that 'not every differentiation of treatment will constitute discrimination, if the criteria for such differentiation are reasonable and objective and if the aim is to achieve a purpose which is legitimate under the Covenant'.[102] Despite the breadth of this right, it does not appear to have been relied on in international jurisprudence to ground a right to assisted dying. The right to equality has also not been raised in cases before the ECtHR in this context.

In Canada, however, the right to equality has been one of the principal rights argued to be engaged under the *Canadian Charter*. It has been argued that a prohibition on assisted suicide is discriminatory because it prevents people with particular physical disabilities, but not the able-bodied, from exercising their right to commit suicide. According to this argument, suicide is a choice which may be rational in some circumstances, and the legal prohibition on assisting suicide imposes a burden on people who are physically unable to commit suicide unaided, by preventing them from making autonomous choices about matters concerning their bodies. Smith J at first instance in *Carter*[103] and Lamer CJ in dissent in *Rodriguez v British Columbia (A-G)*[104]

98 This will be explained further in [11.110].

99 *International Covenant on Civil and Political Rights*, Art 14 also states 'All persons shall be equal before the courts and tribunals. In the determination of any criminal charge against him, or of his rights and obligations in a suit at law, everyone shall be entitled to a fair and public hearing by a competent, independent and impartial tribunal established by law'. This right is a 'series of procedural guarantees' only: Human Rights Committee, *General Comment 32: Article 14: Right to Equality before Courts and Tribunals and to a Fair Trial*, UN Doc CCPR/C/GC/32 (23 August 2007) [2], [58].

100 See also *International Covenant on Economic, Social and Cultural Rights*, Art 2(2); *Convention for the Protection of Human Rights and Fundamental Freedoms*, Art 14; *Convention on the Rights of the Child*, Art 2; *Convention on the Rights of Persons with Disabilities*, Arts 3, 4, 5, 12, among others.

101 Human Rights Committee, *General Comment 18: Non-Discrimination* (1989) [1].

102 Human Rights Committee, n 101, [13].

103 It was not necessary to determine this point on appeal, as the Supreme Court of Canada found that the applicants' rights to life, liberty and security of the person had been violated.

104 *Rodriguez v British Columbia (A-G)* [1993] 3 SCR 519, 549.

(*Rodriguez*) accepted arguments that the right to equality was engaged and breached by a prohibition on physician-assisted dying. It was unnecessary to authoritatively decide the issue when *Carter* reached the Canadian Supreme Court.[105]

Courts in the United Kingdom have disagreed about whether there is a right to commit suicide,[106] and whether the decriminalisation of suicide amounts to society condoning suicide or merely reflects the futility of punishing what is essentially a health concern.[107] Arguments that criminalising assisted suicide breaches the right to equality have been rejected in England, on the basis that the law does not recognise a right to commit suicide, so the right to equality is not engaged, as there is no discrimination in the enjoyment of any right.[108]

Justified limits on human rights

[11.100] Once human rights are defined and found to be engaged, it is necessary for courts to consider whether a restriction on those rights is justified in the furtherance of a legitimate societal purpose. This step recognises that most human rights are not absolute, and that certain limits on the unfettered enjoyment of rights may be justified where the restriction is for a legitimate or compelling social purpose, and the restriction is no more than is reasonably necessary.[109] To evaluate whether restrictions on human rights are justified, courts are required to identify the legislative purpose, and evaluate whether the limitations are rationally connected to achieving that purpose. Courts must also consider whether the limitations impair individual rights to the minimum extent necessary to achieve that purpose, or whether there is a disproportionate impact on individual rights which is not justified by the overarching societal goals.[110]

In the context of the prohibition of VAD, two principal purposes (discussed further below) have been suggested: the *preservation of life* (sometimes,

105 *Carter v Canada (A-G)* [2015] 1 SCR 331 [93].

106 For example, in *Nicklinson*, Lord Wilson referred to the decriminalisation of suicide as establishing a 'positive legal *right* to commit suicide': *R (on the application of Nicklinson) v Ministry of Justice* [2015] AC 657 [200]. In contrast, Lord Sumption stated that although suicide is not a crime, nevertheless it is not morally acceptable, and 'there is no right to commit suicide': *R (on the application of Nicklinson) v Ministry of Justice* [2015] AC 657 [211]-[213].

107 See *Pretty v Director of Public Prosecutions and Secretary of State for the Home Department* [2002] 1 AC 800 [35] (Lord Bingham CJ).

108 See *Pretty v Director of Public Prosecutions and Secretary of State for the Home Department* [2002] 1 AC 800 [35] (Lord Bingham CJ); equality arguments were also raised in *R (on the application of Conway) v The Secretary of State for Justice* [2017] EWHC (Admin) 2447, but abandoned during argument, in part because the right in issue there did not explicitly refer to disability as a ground of discrimination (although it was expressed to be non-exhaustive).

109 See, for example, Bantekas and Oette, n 66, 75.

110 Bantekas and Oette, n 66, 392-394.

including arguments regarding the sanctity of all life), and the *protection of the weak*[111] *and vulnerable* from being induced – directly or indirectly – to end their lives because of fear of burdening others or a sense that their lives lack value. The question for adjudication thus becomes whether an absolute prohibition on VAD is the only safe means to safeguard the rights of the weak and vulnerable and to protect the value of human life, or whether it is possible to design a system with appropriate safeguards that permits access to VAD for some people, while protecting the vulnerable from abuse. This is discussed in more detail in the next section.

HUMAN RIGHTS ARGUMENTS IN THE UNITED KINGDOM, CANADA AND NEW ZEALAND

[11.110] Cases in the United Kingdom, Canada and New Zealand in which the criminalisation of assisted suicide has been challenged on human rights grounds are relevant to Australia because, as described above,[112] Australian courts often make reference to and take guidance from judicial decisions in other common law jurisdictions in situations where an issue has not been judicially determined in Australia. Currently, three Australian jurisdictions have statutory Bills of rights,[113] so it is conceivable that the prohibition on assisted suicide may be challenged in those jurisdictions on human rights grounds. The case law is complex, involving multiple legal issues[114] and voluminous amounts of expert evidence. The discussion in this section is limited to the arguments concerning human rights and the reasons why they were accepted or rejected.

111 The phrase the 'weak and vulnerable' had its origins in the United Kingdom's response to the House of Lords Select Committee on Medical Ethics report concerning assisted suicide: *Pretty v Director of Public Prosecutions and Secretary of State for the Home Department* [2002] 1 AC 800 [28]; *R (on the application of Conway) v The Secretary of State for Justice* [2018] EWCA (Civ) 1431 [11] (Etherton MR, Leveson P, Lady King LJ). This phrase was picked up by judges in some cases as a description of the legislative purpose: *R (on the application of Nicklinson) v Ministry of Justice* [2015] AC 657 [81], [120], [123] (Lord Neuberger CJ), [197] (Lord Wilson); *Pretty v Director of Public Prosecutions and Secretary of State for the Home Department* [2002] 1 AC 800 [94], [96], [97] (Lord Hope). The phrase was most heavily used in *R (on the application of Conway) v The Secretary of State for Justice* [2018] EWCA (Civ) 1431 [51], [61]-[82], [103], [131], [134]-[135], [139], [141], [201]-[205] (Etherton MR, Leveson P, Lady King LJ). This terminology is adopted here by the authors, although we note that this characterisation of certain groups in society is contested.

112 See text accompanying n 10.

113 *Charter of Rights and Responsibilities Act 2006* (Vic); *Human Rights Act 2004* (ACT); *Human Rights Act 2019* (Qld).

114 Such as the doctrine of precedent (*Carter v Canada (A-G)* [2015] 1 SCR 331 [42]-[48]), the doctrine of interjurisdictional immunity (which concerns the division of constitutional power between federal and provincial governments in Canada) (*Carter v Canada (A-G)* [2015] 1 SCR 331 [49]-[53]), and the principles of parliamentary sovereignty and the separation of powers (*R (on the application of Nicklinson) v Ministry of Justice* [2015] AC 657).

United Kingdom

[11.120] The courts in the United Kingdom have heard several cases arguing that the prohibition on assisted suicide violates the rights contained in the *Human Rights Act 1998* (UK) or the ECHR, which entered into force in 1953. Some of these cases challenged the inability of loved ones to provide assistance to die,[115] or to assist a person to travel to Switzerland where assisted suicide is lawful,[116] whereas others took issue with the prohibition on medical professionals providing assistance to die.[117] Three of these cases[118] were determined by the United Kingdom's highest appellate court – the House of Lords, and later the Supreme Court[119] – and a fourth was refused leave to appeal to the Supreme Court, late in 2018.[120]

This section focuses on three of those cases – *Pretty v Director of Public Prosecutions and Secretary of State for the Home Department* (*Pretty*), *R (on the application of Nicklinson and another) v Ministry of Justice* (*Nicklinson*)[121] and *R (on the application of Conway) v Secretary of State for Justice*[122] (*Conway*) – for three reasons. First, these cases directly challenged the law prohibiting assisted suicide, whereas other cases have challenged administrative policies and procedures.[123] A second (and related) reason is that the judgments engaged with human rights arguments in detail, whereas other cases were more concerned with administrative law issues and

115 *Pretty v Director of Public Prosecutions and Secretary of State for the Home Department* [2002] 1 AC 800.

116 *Re Z* [2005] 1 WLR 959; *R (on application of Purdy) v DPP* [2010] AC 345; *R (on the Application of AM) v General Medical Council* [2015] EWHC (Admin) 2096. For more detailed discussion of *Purdy* and the right to privacy, see Brendon Murphy, 'Human Rights, Human Dignity and the Right to Die: Lessons from Europe on Assisted Suicide', (2009) 33 *Criminal Law Journal* 341, 341-343.

117 *R (on the application of Nicklinson) v Ministry of Justice* [2015] AC 657; *R (on the application of Conway) v Secretary of State for Justice* [2018] UKSC (27 November 2018); *T v Secretary of State for Justice* [2017] EWHC (Admin) 3181; *R (On the Application Of T) v Ministry of Justice* [2018] EWHC (Admin) 2615.

118 *Pretty v Director of Public Prosecutions and Secretary of State for the Home Department* [2002] 1 AC 800; *R (on application of Purdy) v DPP* [2010] AC 345; *R (on the application of Nicklinson) v Ministry of Justice* [2015] AC 657.

119 The House of Lords was the ultimate court of appeal in the United Kingdom until 2009, when the Supreme Court was established and vested with that function: *Constitutional Reform Act 2005* (UK).

120 *R (on the application of Conway) v Secretary of State for Justice* [2018] UKSC (27 November 2018).

121 *R (on the application of Nicklinson and another) v Ministry of Justice* [2015] AC 657.

122 *R (on the application of Conway) v Secretary of State for Justice* [2017] EWHC (Admin) 2447; *R (on the application of Conway) v The Secretary of State for Justice* [2018] EWCA (Civ) 1431; *R (on the application of Conway) v Secretary of State for Justice* [2018] UKSC (27 November 2018).

123 These have included prosecutorial policy: *R (on application of Purdy) v DPP* [2010] AC 345; *R (Kenward and Kenward) v DPP and HM Attorney General* [2016] 1 Cr App R 16; the General Medical Council's guidelines for doctors: *R (on the Application of AM) v General Medical Council* [2015] EWHC (Admin) 2096; and the decisions of a local authority: *Re Z* [2005] 1 WLR 959.

remedies.[124] Third, the applicants in these cases were seeking assistance to die in the United Kingdom, whereas other applicants sought assistance to travel to Switzerland to access VAD there.[125]

These three cases also illustrate the development of the law over the last two decades. Initially, in *Pretty*, the House of Lords did not consider any human rights to have been engaged. In the more recent cases of *Nicklinson* and *Conway*, the courts accepted that at least the right to privacy was engaged, and the issue for determination was whether the restriction on the right to privacy was justified by reference to a legitimate purpose.

Pretty (2001)

[11.130] The first case to challenge the criminal prohibition on assisted suicide in the United Kingdom was brought by Dianne Pretty, a 42-year-old woman with progressive motor neurone disease. Because of her physical incapacity (she was paralysed from the neck down), she was unable to end her life without help. She desired the assistance of her husband to end her life before she became unable to swallow or breathe, but wanted an assurance that he would not be prosecuted.[126] Pretty argued that there was a human right to assisted suicide, founded on five rights contained in the ECHR, namely, the right to life;[127] the right to respect for one's private and family life;[128] the prohibition of torture or inhuman or degrading treatment;[129] freedom of thought, conscience and religion;[130] and the prohibition of discrimination.[131] The House of Lords held that none of Pretty's rights was engaged by the prohibition on assisted suicide.[132]

The House of Lords held that the right to life protects the sanctity of life and prohibits the taking of life, including imposing positive obligations on the State to protect life by force-feeding a hunger striker,[133] and preventing

124 Such as whether prosecutorial policy is clear, accessible and consistently implemented: *R (on application of Purdy) v DPP* [2010] AC 345; *R (Kenward and Kenward) v DPP and HM Attorney General* [2016] 1 Cr App R 16; and whether a local authority has power seek an injunction to intervene to prevent a person travelling to Switzerland to seek assistance to die: *Re Z* [2005] 1 WLR 959.

125 *Re Z* [2005] 1 WLR 959; *R (on application of Purdy) v DPP* [2010] AC 345; *R (on the Application of AM) v General Medical Council* [2015] EWHC (Admin) 2096; *T v Secretary of State for Justice* [2017] EWHC (Admin) 3181.

126 *Pretty v Director of Public Prosecutions and Secretary of State for the Home Department* [2002] 1 AC 800 [42]-[44] (Lord Bingham CJ).

127 *Convention for the Protection of Human Rights and Fundamental Freedoms*, Art 2.

128 *Convention for the Protection of Human Rights and Fundamental Freedoms*, Art 8.

129 *Convention for the Protection of Human Rights and Fundamental Freedoms*, Art 3.

130 *Convention for the Protection of Human Rights and Fundamental Freedoms*, Art 9.

131 *Convention for the Protection of Human Rights and Fundamental Freedoms*, Art 14.

132 For a detailed human rights analysis of this case, see Pedain, n 57, 184-192.

133 *X v Germany* (1984) 7 EHRR 152.

suicide of a person in custody.[134] Accordingly, it cannot be interpreted as including a 'right to die' or a 'right to choose whether or not to live'.[135] Lord Hope of Craighead explained that, 'The [right to life] is all about protecting life, not bringing it to an end. It is not possible to read it as obliging the state to allow someone to assist another person to commit suicide'.[136]

Similarly, the House of Lords rejected an argument that the right to respect for one's private life conferred a right to self-determination which 'embraces a right to choose when and how to die so that suffering and indignity can be avoided'.[137] Instead, it held that privacy is restricted to respect for a person's autonomous choices while living his or her life. Interpreting the right to a private life to encompass a right to die would extinguish the very benefit of possessing that right:

> article 8 is expressed in terms directed to protection of personal autonomy while individuals are living their lives, and there is nothing to suggest that the article has reference to the choice to live no longer.[138]

Therefore, the criminal prohibition on assisted suicide did not engage Pretty's right to privacy.[139] In the alternative, if her right under Art 8 was engaged, any interference with that right was held to be justified as a proportionate and appropriate response to the need to protect the weak and vulnerable from abuse.[140]

The argument that the State breached its obligation not to inflict 'torture or inhuman or degrading treatment or punishment'[141] on Mrs Pretty was not seriously entertained by the House of Lords. Mrs Pretty argued that she was suffering due to the progression of her disease, and the State had the ability to alleviate her suffering by undertaking not to prosecute Mr Pretty if he assisted his wife to commit suicide. It was argued that the failure to give an undertaking which would enable Mr Pretty to assist his wife end her suffering amounted to torture or inhuman or degrading treatment. The

134 *Keenan v United Kingdom* [2001] ECHR 242.

135 *Pretty v Director of Public Prosecutions and Secretary of State for the Home Department* [2002] 1 AC 800 [4] (Lord Bingham CJ).

136 *Pretty v Director of Public Prosecutions and Secretary of State for the Home Department* [2002] 1 AC 800 [88] (Lord Hope).

137 *Pretty v Director of Public Prosecutions and Secretary of State for the Home Department* [2002] 1 AC 800 [17] (Lord Bingham CJ).

138 *Pretty v Director of Public Prosecutions and Secretary of State for the Home Department* [2002] 1 AC 800 [23] (Lord Bingham CJ); see also [61] (Lord Steyn).

139 *Pretty v Director of Public Prosecutions and Secretary of State for the Home Department* [2002] 1 AC 800 [26] (Lord Bingham CJ); [61] (Lord Steyn); [99]-[101] (Lord Hope); [112] (Lord Hobhouse); [124] (Lord Scott).

140 *Pretty v Director of Public Prosecutions and Secretary of State for the Home Department* [2002] 1 AC 800 [26]-[30] (Lord Bingham CJ), [62] (Lord Steyn), [102] (Lord Hope), [112] (Lord Hobhouse), [124] (Lord Scott).

141 Within the meaning of the *Convention for the Protection of Human Rights and Fundamental Freedoms*, Art 3.

House of Lords rejected this contention, stating that Mrs Pretty's suffering 'derives from her cruel disease' not from any conduct of the State.[142] In any event, any restriction of her human rights would be justified as proportionate to the legitimate objective of protecting the weak and vulnerable.[143]

The right to freedom of thought, conscience and religion was found not to be engaged, because it does not extend to a requirement that a person be able to act on their beliefs in a way which is proscribed by the criminal law.[144] Finally, Pretty argued that the prohibition on assisted suicide 'is discriminatory because it prevents the disabled, but not the able-bodied, exercising their right to commit suicide'.[145] The House of Lords found this argument misconceived. The prohibition on discrimination is not freestanding but protects only discrimination in the enjoyment of ECHR rights.[146] As Pretty had no right to commit suicide, and this was not protected under any of her other Convention rights, there was no discrimination in the enjoyment of any right.[147]

Pretty unsuccessfully appealed to the ECtHR, which held that her right to respect for her private life under Art 8 was engaged, but not breached, because the prohibition on assisted suicide was within the margin of appreciation[148] accorded to individual States. That is, the United Kingdom was within the discretion accorded to it as a sovereign state to determine that the best method of balancing the right to self-determination against the need

142 *Pretty v Director of Public Prosecutions and Secretary of State for the Home Department* [2002] 1 AC 800 [13] (Lord Bingham CJ), [60] (Lord Steyn).

143 *Pretty v Director of Public Prosecutions and Secretary of State for the Home Department* [2002] 1 AC 800 [95]-[97] (Lord Hope).

144 *Pretty v Director of Public Prosecutions and Secretary of State for the Home Department* [2002] 1 AC 800 [31] (Lord Bingham CJ), [63] (Lord Steyn).

145 *Pretty v Director of Public Prosecutions and Secretary of State for the Home Department* [2002] 1 AC 800 [35] (Lord Bingham CJ).

146 *Van Raalte v Netherlands* (1997) 24 EHRR 503, 516 [33]; *Botta v Italy* (1998) 26 EHRR 241 at 259 [39].

147 *Pretty v Director of Public Prosecutions and Secretary of State for the Home Department* [2002] 1 AC 800 [33]-[34] (Lord Bingham CJ), [64] (Lord Steyn).

148 The term 'margin of appreciation' is not found in the *Convention for the Protection of Human Rights and Fundamental Freedoms* itself, but is commonly found in judgments of the ECtHR. It was first articulated in *Handyside v United Kingdom* (1976) 1 EHRR 737, and is used to accord discretion to states in the method employed to implement *Convention* rights domestically, particularly on matters such as this, involving public morals. It reflects the principle of subsidiarity, which recognises the sovereignty of individual nation states and holds that states have primary responsibility for guaranteeing the human rights contained in the *Convention*. See Bantekas and Oette, n 66, 245. The European Court has recognized that a wider range of legislative regimes can be considered consonant with the human rights contained in the *Convention* when an issue is socially complex, where there is a lack of consensus among European nations, and where the issue requires a balance to be struck between competing human rights or public and private interests: *Mueller v Switzerland* (1988) 13 EHRR 212; *Dickson v United Kingdom* [2007] ECHR 1050.

to protect the weak and vulnerable was to impose a blanket ban on assisted suicide in all circumstances.[149]

Subsequent English cases[150] which challenged the prohibition on assisted suicide, including *Nicklinson* and *Conway*, have focused on the right to respect for one's private life,[151] and other rights have generally not been argued.[152]

Nicklinson (2014)

[11.140] Nicklinson's case concerned three men[153] who suffered long-term paralysis but were not terminally ill. As a result of a catastrophic stroke, Tony Nicklinson had suffered 'locked in' syndrome for nine years. He was completely paralysed and could move only his head and eyes. The second applicant, known only by the pseudonym 'Martin', was also almost totally paralysed as a result of a brain stem stroke.[154] Both Nicklinson and Martin communicated laboriously via an eye blink computer. The third applicant, Paul Lamb, had been paralysed by a car accident over 20 years ago and was able only to move his right hand. All three men considered their lives intolerable, but because of physical limitations could only end their lives by self-starvation (refusing all food and water) or with assistance.[155] The

149 Where it has been argued that the prohibition on VAD infringes the *Convention for the Protection of Human Rights and Fundamental Freedoms*, these arguments have failed, as the ECtHR has held that such a legislative scheme is within the 'margin of appreciation' accorded to individual nation states. See *Pretty v United Kingdom* (2002) 35 EHRR 1; *Nicklinson and Lamb v United Kingdom* [2015] ECHR 709.

150 *R (on the application of Nicklinson) v Ministry of Justice* [2015] AC 657; *R (on the application of Conway) v The Secretary of State for Justice* [2017] EWHC (Admin) 2447; *R (on the Application of AM) v General Medical Council* [2015] EWHC (Admin) 2096; *R (on application of Purdy) v DPP* [2010] AC 345.

151 *Convention for the Protection of Human Rights and Fundamental Freedoms*, Art 8.

152 In two recent English cases – *T v Secretary of State for Justice* [2017] EWHC (Admin) 3181 and *R (on the application of Newby) v Secretary of State for Justice* [2019] EWHC 3118 (Admin) – the applicant claimed a violation of the right to life in addition to the right to privacy. However, the substantive issues were not judicially determined in either case. T went to Switzerland and received assistance to die while the case remained in the interlocutory stages: *T v Secretary of State for Justice* [2017] EWHC (Admin) 3181; *R (On the Application Of T) v Ministry of Justice* [2018] EWHC (Admin) 2615. And in *Newby*, the English High Court refused permission for judicial review, because it considered itself bound by the decision in *Conway*.

153 The case was initially brought by Nicklinson alone, but after it was unsuccessful in the English High Court, Nicklinson commenced self-starvation, refusing all food, and died as a result of pneumonia in August 2012: *R (on the application of Nicklinson) v Ministry of Justice* [2015] AC 657 [6]. Nicklinson's wife pursued the case on her late husband's behalf to the UK Supreme Court and the ECtHR in Strasbourg. But because of concerns about her standing to bring proceedings, Lamb and Martin were added as plaintiffs: *R (on the application of Nicklinson) v Ministry of Justice* [2015] AC 657 [8].

154 Martin was able to make slow hand movements.

155 Nicklinson's preference was for active assistance by lethal injection, however, by the time the case came before the Supreme Court, argument was focused on the self-administration of a lethal drug using a machine developed by Australian doctor Philip Nitschke, which

applicants argued that the criminal prohibition against assisting a suicide was an infringement of their human rights.[156]

The applicants in this case argued that the prohibition on assisted suicide under English law was an unnecessary and disproportionate restriction on their right to a private life.[157] The Supreme Court did not conclusively determine the issue of whether the prohibition was incompatible with the right to a private life,[158] because a majority of the Court considered it to be 'institutionally inappropriate' for the Court to rule on this issue when a Bill was currently before the Parliament.[159]

However, the majority judges in *Nicklinson* clearly accepted that the right to respect for one's private life was engaged, as it 'encompasses the right to decide how and when to die, and in particular the right to avoid a distressing and undignified end to life (provided that the decision is made freely)'.[160] Lord Wilson referred to this as a 'positive legal *right* to commit suicide',[161]

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could be activated by a passphrase entered using eye blinks: *R (on the application of Nicklinson) v Ministry of Justice* [2015] AC 657 [4].

156 If a declaration of incompatibility with the *Human Rights Act 1998* (UK) were made, the prohibition on assisted suicide would not become void or unlawful, because a declaration 'does not affect the validity, continuing operation or enforcement of the provision', nor is the declaration 'binding on the parties': *Human Rights Act 1998* (UK), s 4(6). But the applicants hoped such a declaration would lead to legislative change via the parliamentary process. For a discussion of the human rights arguments, see Martin, n 58, 100-102.

157 This right is contained in the *Human Rights Act 1998* (UK), Sch 1, Art 8 which is identical in terms to the *Convention for the Protection of Human Rights and Fundamental Freedoms*, Art 8. Because the ECtHR had determined that the prohibition of assisted suicide fell within the wide 'margin of appreciation' accorded to States under the *Convention for the Protection of Human Rights and Fundamental Freedoms*, this case was argued on the basis that the prohibition infringed domestic law under the *Human Rights Act 1998* (UK). The United Kingdom has power to decide for itself whether human rights have been infringed, and is not bound merely to apply European jurisprudence: *R (on the application of Nicklinson) v Ministry of Justice* [2015] AC 657 [70]-[73] (Lord Neuberger), [230] (Lord Sumption with Lords Clarke, Reed and Hughes agreeing), [299] (Lady Hale), [340] (Lord Kerr), all citing *In re G (Adoption: Unmarried Couple)* [2009] 1 AC 173.

158 *Human Rights Act 1998* (UK), s 4(2). Lord Neuberger also referred to the independent right of a close family member seeking to assist a person who wishes to die, to respect for their own right to privacy (although this was not a major feature of the case): *R (on the application of Nicklinson) v Ministry of Justice* [2015] AC 657 [20] (Lord Neuberger citing *Koch v Germany* (2013) 56 EHRR 6 [43]-[46]).

159 *R (on the application of Nicklinson) v Ministry of Justice* [2015] AC 657 [113]-[118] (Lord Neuberger), [188], [190]-[191] (Lord Mance), [196]-[197] (Lord Wilson with Lord Clarke agreeing at [293]). Lord Sumption, with Lords Reed, Clarke and Hughes agreeing, dissented on this issue. They felt the choice between fundamental but inconsistent moral values that was involved in the determination of this case was 'institutionally inappropriate' for courts, and was a matter exclusively for Parliament to determine: [230].

160 *R (on the application of Nicklinson) v Ministry of Justice* [2015] AC 657 [29] (Lord Neuberger quoting *Haas v Switzerland* (2011) 53 EHRR 33 [51]; *Koch v Germany* (2013) 56 EHRR 6 [46], [51]; and *Gross v Switzerland* (2014) 58 EHRR 7 [60]).

161 *R (on the application of Nicklinson) v Ministry of Justice* [2015] AC 657 [200].

but Lord Sumption doubted whether a legal right to commit suicide exists, describing it instead as an 'immunity from interference by the state'.[162]

The question which then arose for determination was whether the blanket ban on assisting suicide is justified, as a *necessary* restriction on the right to private life in furtherance of legitimate ends,[163] or is *disproportionate* to those ends.[164] Eight of the nine judges considered a prohibition on assisted suicide was rationally connected[165] to a legitimate legislative objective: namely, 'to safeguard life, and in particular the lives of the vulnerable and the weak'.[166] The role of the courts was, accordingly, to 'weigh social risks to the wider public and the moral convictions of a body of members of the public together with values of human autonomy and of human dignity in life and death advocated by other members'.[167]

Four judges declined to decide the issue, because of the Bill before Parliament.[168] Lord Sumption (with whom Lords Hughes and Reed agreed) considered that a prohibition on assisted suicide was necessary, given the risk that the weak and vulnerable may feel that their lives are valueless or a burden, and may feel an indirect pressure to end their lives.[169] Only Lady Hale and Lord Kerr found that the prohibition was disproportionate and unnecessary, because it prejudiced those who were not vulnerable in order to protect those who may be vulnerable.[170] Hence, they were prepared to

162 *R (on the application of Nicklinson) v Ministry of Justice* [2015] AC 657 [216]. See generally [211]-[216] and the views of Lord Hughes at [264].

163 Article 8(2) permits interference with Art 8(1) right to privacy if that interference is 'necessary in a democratic society' for one or more of the following purposes: 'the prevention of disorder or crime', 'the protection of health or morals' or 'the protection of the rights and freedoms of others'.

164 The test of proportionality is derived from *R (Aguilar Quila) v The Secretary of State for the Home Department* [2012] 1 AC 621 [45] (Lord Wilson). See also *Bank Mellat v HM Treasury (No 2)* [2013] UKSC 39; [2013] 3 WLR 179 [68]-[76] (Lord Reed).

165 *R (on the application of Nicklinson) v Ministry of Justice* [2015] AC 657 [81] (Lord Neuberger), [171] (Lord Mance), [228] (Lord Sumption, with Lords Hughes, Reed and Clarke agreeing), [311] (Lady Hale). Lord Kerr was alone in considering that there was no rational connection between the aim of the legislation to protect the vulnerable, and the prohibition on assisting suicide: [349]-[351], [361].

166 Lord Sumption also referred to a second objective: namely, the protection of morals through preservation of the sanctity of life: *R (on the application of Nicklinson) v Ministry of Justice* [2015] AC 657 [235], but Lady Hale and Lord Neuberger doubted whether this would constitute the 'protection of morals'. Lady Hale observed that people have different moral ideas on what is right and wrong: [311], and Lord Neuberger opined that moral arguments on the sanctity of life mean little more than protecting the weak and vulnerable: [90].

167 *R (on the application of Nicklinson) v Ministry of Justice* [2015] AC 657 [191] (Lord Mance).

168 Lords Neuberger, Mance, Wilson and Clarke.

169 *R (on the application of Nicklinson) v Ministry of Justice* [2015] AC 657 [228] (Lord Sumption). These views are strictly *obiter dicta*, given Lord Sumption's conclusion that it was institutionally inappropriate for the Court to consider the issue of incompatibility.

170 *R (on the application of Nicklinson) v Ministry of Justice* [2015] AC 657 [312]-[313] (Lady Hale), [352] (Lord Kerr). Lords Mance, Wilson and Clarke would also have declined to make

declare that the prohibition on assisted suicide was incompatible with the applicants' human rights. Both judges in the minority noted, however, that a right to respect for autonomous choices does not entail a right to demand assistance to achieve them.[171]

Given the importance of the issue (as evidenced by the number of cases which have been brought in the United Kingdom), and the comprehensive argument before the UK Supreme Court, it is disappointing that the judgment in this case did little to clarify whether the criminal prohibition on assisted suicide infringes human rights or is justified as a proportionate and necessary limit imposed in furtherance of a legitimate policy objective. This is particularly disappointing, given the primary reason for declining to answer the question was deference to Parliament, and in the end, Parliament did not fully consider or vote on the Bill before it.[172]

Conway (2018)

[11.150] Lord Neuberger in *Nicklinson* suggested that the Supreme Court would be willing to reconsider the issue when an appropriate case came before the courts.[173] Noel Conway thought his case was the appropriate vehicle for that reconsideration, and gathered extensive evidence, including setting forth a detailed proposal for a scheme for the regulation of VAD.

Noel Conway is a 69-year-old retired lecturer with motor neurone disease, confined to a wheelchair and dependent on ventilation to breathe for an increasing number of hours per day. In 2017, he brought a challenge to the criminal prohibition on assisted suicide. Conway expressed his desire for assistance to have a peaceful and dignified death, at a point in time when he had less than six months to live. He argued that the English prohibition on assisted suicide breached his right to respect for his private life[174] and

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a judgment on proportionality due to a lack of reliable expert evidence of risks to the vulnerable: [175]-[182] (Lord Mance), [197]-[201] (Lord Wilson), [292] (Lord Clarke). For more detailed discussion of the judgments in the case, see Stevie Martin, 'Declaratory Misgivings: Assisted Suicide in a Post-Nicklinson Context', [2018] *Public Law* 209.

171 *R (on the application of Nicklinson) v Ministry of Justice* [2015] AC 657 [307] (Lady Hale), [329] (Lord Kerr).

172 The Assisted Dying Bill 2014 of Lord Falconer was introduced in the House of Lords on 6 June 2014, was debated and began its committee stage in January 2015, but did not proceed to a vote, and lapsed when Parliament was prorogued on 26 March 2015. Accordingly, only one House of Parliament debated the Bill, and neither House had an opportunity to vote on the Bill before it lapsed. The issue has received further consideration by the UK Parliament: from 2015 to 2017, three more private members Bills aiming to legalise VAD have been introduced, one was debated and rejected by 330 votes to 118; *R (on the application of Conway) v The Secretary of State for Justice* [2017] EWHC (Admin) 2447 [51] (Lord Sales LJ, Whipple and Garnham JJ); *R (on the application of Conway) v The Secretary of State for Justice* [2018] EWCA (Civ) 1431 [41]-[48] (Etherton MR, Leveson P and Lady King LJ); Martin, n 58, 101.

173 *R (on the application of Nicklinson) v Ministry of Justice* [2015] AC 657 [101].

174 *Convention for the Protection of Human Rights and Fundamental Freedoms*, Art 8.

to freedom from discrimination.[175] The non-discrimination argument was abandoned during the hearing, as the terms of the right did not explicitly recognise 'disability' as a ground of discrimination, although it was recognised that the grounds of discrimination are non-exhaustive.

In contrast to *Nicklinson*, both the High Court and the Court of Appeal accepted three legitimate purposes of the English law: namely, the protection of the weak and vulnerable; the protection of morals through the protection of the sanctity of life; and the protection of health through the promotion of trust and confidence between doctor and patient.[176] Both courts considered that Parliament was justified in maintaining the prohibition, and in considering a blanket ban was necessary to protect the weak and vulnerable who may be prone to despair or feeling like a burden to others, and may experience indirect societal pressure to request assistance in dying.[177] They considered the necessity was even stronger when considering the other two legislative objectives – the sanctity of life[178] and protection of the doctor-patient relationship.[179] Accordingly, Mr Conway was not successful in obtaining a declaration of incompatibility.[180] It was significant in this case that Mr Conway could lawfully choose to die by requesting the withdrawal of his artificial ventilation,[181] an option unavailable to the applicants in *Nicklinson*. Death by withdrawal of artificial ventilation usually occurs within minutes, sometimes hours, whereas death by self-starvation (the only option available to the applicants in *Nicklinson*) is protracted and painful, lasting days or weeks.[182]

175 *Convention for the Protection of Human Rights and Fundamental Freedoms*, Art 14.

176 *R (on the application of Conway) v The Secretary of State for Justice* [2017] EWHC (Admin) 2447 [91]-[94] (Lord Sales LJ, Whipple and Garnham JJ); *R (on the application of Conway) v The Secretary of State for Justice* [2018] EWCA (Civ) 1431 [139] (Etherton MR, Leveson P, Lady King LJ).

177 *R (on the application of Conway) v The Secretary of State for Justice* [2017] EWHC (Admin) 2447 [100]-[103], [109]-[110] (Lord Sales, Whipple and Garnham JJ); *R (on the application of Conway) v The Secretary of State for Justice* [2018] EWCA (Civ) 1431 [160]-[163], [205] (Etherton MR, Leveson P, Lady King LJ).

178 *R (on the application of Conway) v The Secretary of State for Justice* [2017] EWHC (Admin) 2447 [100]-[103], [112] (Lord Sales LJ, Whipple and Garnham JJ); *R (on the application of Conway) v The Secretary of State for Justice* [2018] EWCA (Civ) 1431 [160]-[163], [205] (Etherton MR, Leveson P, Lady King LJ).

179 *R (on the application of Conway) v The Secretary of State for Justice* [2017] EWHC (Admin) 2447 [100]-[103], [113] (Lord Sales LJ, Whipple and Garnham JJ); *R (on the application of Conway) v The Secretary of State for Justice* [2018] EWCA (Civ) 1431 [150]-[158], [205] (Etherton MR, Leveson P, Lady King LJ).

180 Leave to appeal to the UK Supreme Court was refused on 27 November 2018.

181 *R (on the application of Conway) v The Secretary of State for Justice* [2017] EWHC (Admin) 2447 [31]-[32], [117] (Lord Sales LJ, Whipple and Garnham JJ).

182 'Martin' had previously attempted to die by self-starvation, but had abandoned it 'in distressing circumstances': *R (on the application of Nicklinson) v Ministry of Justice* [2015] AC 657 [12]. Nicklinson eventually succeeded in dying by self-starvation after the decision of the English High Court in his case. This course of action took about a week, and was

The UK Supreme Court refused leave to appeal from the judgment of the Court of Appeal,[183] leaving the issue of a right to VAD yet to be authoritatively determined by the United Kingdom's highest court.

Canada

[11.160] The Supreme Court of Canada considered whether the prohibition on assisted suicide breached the *Canadian Charter* in two seminal cases, decided more than 20 years apart. In the first case, *Rodriguez*, the Court by a narrow majority of 5:4 decided that the interference with the right to life, liberty and security of the person was proportionate and hence justified, whereas in *Carter*, the Court unanimously reversed *Rodriguez*, holding that the serious nature of the interference with such rights was not proportionate to any legitimate social purpose.

Rodriguez (1993)

[11.170] Sue Rodriguez was a 42-year-old mother dying of motor neurone disease.[184] As her disease progressed, she would lose the ability to swallow, speak, walk, move and eventually breathe without assistance. She wanted a doctor to set up technological means by which she could die by her own hand once her suffering became intolerable.[185] She argued the prohibition on assisted suicide in the Canadian *Criminal Code* violated her Charter rights, specifically the right to life, liberty and security of the person[186] and equality.[187]

It was generally accepted by all nine judges of the Canadian Supreme Court that the Charter right to 'security of the person' was engaged, as it encompasses personal autonomy, including the right to freedom from State interference with a person's physical and psychological integrity. The prohibition on physician-assisted suicide is a clear violation of the principle of personal autonomy, and also causes physical pain and psychological distress, which impinge on the right to security of the person. However, the five judges who were in the majority in *Rodriguez* held that the prohibition

described by Lord Neuberger as 'difficult and painful': *R (on the application of Nicklinson) v Ministry of Justice* [2015] AC 657 [6].

183 *R (on the application of Conway) v Secretary of State for Justice* [2018] UKSC (27 November 2018).

184 The judgments of the Canadian courts refer to Mrs Rodriguez as suffering from amyotrophic lateral sclerosis, which is an alternative term for motor neurone disease (it is also sometimes referred to as Lou Gehrig's disease). For consistency, the disease is here referred to as motor neurone disease.

185 *Rodriguez v British Columbia (A-G)* [1993] 3 SCR 519, 530-531.

186 *Canadian Charter of Rights and Freedoms*, s 7.

187 *Canadian Charter of Rights and Freedoms*, s 15. It was also argued that the prohibition constituted 'cruel and unusual treatment', in violation of the *Canadian Charter of Rights and Freedoms*, s 12 but this argument was not entertained by the Court in any depth: *Rodriguez v British Columbia (A-G)* [1993] 3 SCR 519, 610-612.

was justified[188] as a proportionate and appropriate response to legitimate societal interests.

The majority of the Court declined to expressly rule that the right to equality was engaged by a prohibition on assisted suicide, but did express the view that any interference with Rodriguez's right to equality[189] was also justified. The societal interests which were identified by the majority were the need to protect the vulnerable and the need to protect and maintain respect for human life by prohibiting the taking of life.[190] They considered the law regarding the decriminalisation of suicide, and other forms of medical decision-making at the end of life, and concluded that the law maintains a 'bright line' and legally relevant distinction between active and passive forms of intervention at the end of life. They concluded that there was no 'half-way measure' – no legislative safeguards – which could be relied on with assurance to protect the vulnerable, hence the blanket prohibition was justified.

Of the four dissenting judges in *Rodriguez*, two held that the prohibition violated the right to equality, as it prevented people with severe physical disability who are 'physically unable to end their lives unassisted from choosing suicide when that option is, in principle, available to other members of the public'.[191] Three of the four judges held that the prohibition infringed the right to security of the person, which protects the right to personal autonomy, and self-determination in decisions about matters concerning one's body.[192] None of the dissenters considered that the violation of these rights was justified as within 'reasonable limits' in furtherance of a pressing and substantial legislative objective.[193] They focused on the subjective perception of the value of life and its dignity,[194] as well as the fact that an absolute prohibition on assisted suicide restricts the rights of those who are

188 Justification is considered twice in the *Canadian Charter* jurisprudence: first, s 7 itself allows deprivation of the right to life, liberty and security of the person 'in accordance with the principles of fundamental justice', and second, s 1 contains the general qualification that all rights contained within the *Canadian Charter of Rights and Freedoms* are subject to 'such reasonable limits prescribed by law as can be demonstrably justified in a free and democratic society'.

189 *Rodriguez v British Columbia (A-G)* [1993] 3 SCR 519, 612-613.

190 *Rodriguez v British Columbia (A-G)* [1993] 3 SCR 519, 613.

191 *Rodriguez v British Columbia (A-G)* [1993] 3 SCR 519, 549 (Lamer CJ with Cory J agreeing).

192 *Rodriguez v British Columbia (A-G)* [1993] 3 SCR 519, 617 (McLachlin J with L'Heureux-Dubé J and Cory J agreeing). Lamer CJ made similar comments concerning self-determination at 552-553, but did not expressly hold that the right to life, liberty and security of the person had been infringed.

193 Section 1 of the *Canadian Charter of Rights and Freedoms* contains a general limitation that rights can be restricted if the restriction is within 'such reasonable limits prescribed by law as can be demonstrably justified in a free and democratic society', but these restrictions were not held to be reasonable or justified.

194 *Rodriguez v British Columbia (A-G)* [1993] 3 SCR 519, 624 (McLachlin J with L'Heureux-Dubé J and Cory J agreeing).

not vulnerable in order to protect those who are vulnerable.[195] In their view, self-determination should be primary, so long as safeguards exist to ensure there is no evidence of vulnerability or duress.

Carter (2015)

[11.180] In 2012, almost 20 years after the *Rodriguez* decision, another challenge was launched.[196] The primary plaintiff in *Carter* was Gloria Taylor, who, like Sue Rodriguez, was suffering from motor neurone disease. She did 'not want to die slowly, piece by piece' or 'wracked with pain',[197] but wished to die peacefully, at a time of her choosing, when her quality of life had deteriorated to the point that she no longer wished to live. Gloria Taylor's action was joined by the daughter and son-in-law of Kay Carter.[198] They had assisted their mother/mother-in-law (suffering from severe spinal stenosis[199]) to travel to Switzerland to end her life. This option was not available to Gloria Taylor due to a lack of financial resources.

At trial, Lynn Smith J of the Supreme Court of British Columbia held that the prohibition violated both the right to equality[200] and the right to life, liberty and security.[201] This was reversed by the British Columbia Court of Appeal,[202] which considered the *Rodriguez* decision to be binding precedent on lower courts. The Supreme Court of Canada unanimously held that the prohibition violated the right to life, liberty and security of the person, and, therefore, found it unnecessary to determine the claim based on equality.[203]

The Supreme Court of Canada rejected the argument that the right to life included a right to die, or a right to quality of life,[204] and held instead that

195 *Rodriguez v British Columbia (A-G)* [1993] 3 SCR 519, 563 (Lamer CJ), 626-627 (McLachlin J with L'Heureux-Dubé J agreeing). Cory J agreed with both Lamer CJ and McLachlin J.

196 An earlier challenge brought in 2001 was rejected, following *Rodriguez* as precedent: *Wakeford v Canada* (2001) 81 CRR 342 (Ontario Supreme Court), upheld (2002) 58 OR 65 (Ontario Court of Appeal), leave to appeal to SCC refused [2002] SCCA No 72.

197 *Carter v Canada (A-G)* [2015] 1 SCR 331 [11].

198 The claims of Lee Carter and Hollis Johnson (Kay Carter's daughter and son-in-law), that the law restricted their Charter rights by exposing them to potential criminal sanction for assisting in suicide, were not the focus of arguments raised at trial, and they did not seek a remedy, so the claim was not determined by the Supreme Court: *Carter v Canada (A-G)* [2015] 1 SCR 331 [69].

199 Her condition involved progressive compression of the spinal cord accompanied by severe pain.

200 The argument was that physically disabled individuals are prevented from taking their own lives because they are unable to do so without assistance, whereas able-bodied individuals are not so restricted. The inequality is said to stem from the fact that suicide is no longer a crime under Canadian law, but assisting suicide remains a crime.

201 *Carter v Canada (Attorney General)* [2012] BCSC 886 [1322].

202 *Carter v Canada* [2013] 51 BCLR (5th) 213 [84]-[89].

203 *Carter v Canada (A-G)* [2015] 1 SCR 331.

204 *Carter v Canada (A-G)* [2015] 1 SCR 331 [59], [62]. For commentary on this case, see Jocelyn Downie, 'Permitting Voluntary Euthanasia and Assisted Suicide: Law Reform Pathways

it protected life *against* threats of death. However, the Court found that the right to life was infringed, because the prohibition on assisted suicide created an increased risk that people in the position of Ms Taylor may commit suicide prematurely, for fear that they would be incapable of doing so when they reached the point where suffering was intolerable.[205] The Court also found that the right to liberty, which protects 'the right to make fundamental personal choices free from state interference'[206] and the right to security of the person (encompassing personal autonomy and control over one's bodily integrity) were engaged.

The Supreme Court held that the prohibition on assisted suicide interferes with fundamental personal choices concerning medical care, which may be of critical importance to a person's sense of dignity and self-control. This restriction was not proportionate to the legitimate legislative objective of protecting vulnerable people from being induced to commit suicide, and thus was constitutionally invalid.[207] The Supreme Court issued a declaration that the relevant provisions of the *Criminal Code* were void insofar as they prohibited physician-assisted death for a competent adult who clearly consented to the termination of life and had a grievous and irremediable medical condition (including an illness, disease or disability) that caused enduring suffering that was intolerable to the individual in the circumstances of their condition. The Supreme Court found that the trial judge had before her evidence that a permissive regime with properly designed and administered safeguards was capable of protecting vulnerable people from abuse and error, while allowing non-vulnerable people to exercise self-determination in the time and manner of their death.[208]

for Common Law Jurisdictions', (2016) 16(1) *Queensland University of Technology Law Review* 84.

205 *Carter v Canada (A-G)* [2015] 1 SCR 331 [57]-[58]. Ms Taylor deposed that she was faced with the 'cruel choice between killing herself while she was still physically capable of doing so, or giving up the ability to exercise any control over the manner and timing of her death': *Carter v Canada (A-G)* [2015] 1 SCR 331 [13].

206 *Carter v Canada (A-G)* [2015] 1 SCR 331 [64], citing *Blencoe v British Columbia (Human Rights Commission)* [2000] 2 SCR 307 [54].

207 *Carter v Canada (A-G)* [2015] 1 SCR 331 [126].

208 *Carter v Canada (A-G)* [2015] 1 SCR 331 [117]. In response to the *Carter* decision, the Canadian Parliament passed a law that came into force on 17 June 2016, which permitted VAD subject to meeting a range of eligibility criteria and procedural safeguards: *An Act to Amend the Criminal Code and to Make Related Amendments to Other Acts*, SC 2016, c 3. Subsequent challenges to the validity of this law were brought on 11 September 2019, in *Truchon and Gladu v Attorney-General of Canada* (2019) QCCS 3792, and aspects of the eligibility criteria were ruled by the Quebec Superior Court to be constitutionally invalid. In response to this judgment, the federal government introduced *Medical Assistance in Dying Act*. This Bill has passed the first reading stage in the federal House of Commons and is in the midst of second reading debates.

New Zealand

[11.190] Shortly after the Canadian Supreme Court's decision in *Carter*, the New Zealand High Court considered a similar challenge to that country's laws. In *Seales*, it was argued that the legal prohibition on assisted suicide was inconsistent with the *New Zealand Bill of Rights Act 1990* (NZ). Similar arguments were made to those presented and accepted by the unanimous Supreme Court of Canada in *Carter*. Although Collins J relied heavily on the reasoning in *Carter* in writing his judgment, ultimately he reached the opposite conclusion; namely, that the law criminalising assisted suicide was not a violation of the applicant's human rights.[209]

Seales (2015)

[11.200] Lecretia Seales was a 42-year-old New Zealand lawyer dying of an inoperable brain tumour, who was partially paralysed, visually impaired and dependent on others for many day-to-day needs.[210] She argued that the law prohibiting assisted suicide[211] was inconsistent with the right to life and the right not to be subjected to cruel treatment contained in the *New Zealand Bill of Rights Act 1990* (NZ).[212] The latter claim was rejected, as it had been by the Supreme Court of Canada in *Rodriguez* and the House of Lords in *Pretty*, because Ms Seales' circumstances were not the result of any 'treatment' by the State, but were a direct consequence of her tumour.[213]

The case was heard by Collins J, a single judge of the High Court. He held that the right to life, as articulated in the *New Zealand Bill of Rights Act 1990* (NZ), does not include the right to liberty and security of the person, so (unlike Canadian law) does not incorporate personal autonomy interests.[214] Nevertheless, Collins J accepted the argument made in *Carter* that the right to life is engaged where the law imposes an increased risk of death.[215] In a situation such as this, a person in Ms Seales' predicament may choose to prematurely end her life, aware of the unavailability of assisted suicide when her condition has deteriorated to the point that she lacks the physical ability to take action to end her life unaided.[216]

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209 This discrepancy has been the subject of criticism: Martin, n 58.

210 *Seales v Attorney-General* [2015] 3 NZLR 556 [26].

211 *Crimes Act 1961* (NZ), s 179(b). She also challenged the homicide provision in the *Crimes Act 1961* (NZ), s 160, arguing that it prohibited voluntary euthanasia.

212 The *New Zealand Bill of Rights Act 1990* (NZ), s 8 provides that 'No one shall be deprived of life except on such grounds as are established by law and are consistent with the principles of fundamental justice'. Section 9 contains the right not to be tortured or subjected to cruel treatment.

213 *Seales v Attorney-General* [2015] 3 NZLR 556 [197]-[200].

214 *Seales v Attorney-General* [2015] 3 NZLR 556 [156].

215 *Seales v Attorney-General* [2015] 3 NZLR 556 [164].

216 *Seales v Attorney-General* [2015] 3 NZLR 556 [165]. There was evidence that 3%-8% of suicides in New Zealand from 1900 to 2000 were committed by people suffering a terminal

Although Collins J relied heavily on the Canadian analysis of the proportionality of the law to a legitimate legislative purpose,[217] he reached the opposite conclusion to the Canadian decision in *Carter*. He concluded that the right to life was not breached, because he characterised the purpose of the law as 'the absolute protection of the lives of all who are vulnerable .... [and] so far as is reasonably possible, the lives of those who are not vulnerable'.[218] Laws prohibiting assisted suicide were not disproportionate to the purpose of protecting all life.[219] Thus, it remained illegal for Ms Seales' doctor to supply her with a lethal drug which would enable her to end her life at the time of her choosing.

Concluding observations

[11.210] Apart from the early decision of the House of Lords in *Pretty*, courts have universally found that the human rights of those wishing to access VAD are engaged by a criminal prohibition on assisted suicide. The right most commonly found to be engaged is the right to personal autonomy in decision-making, which is protected in the United Kingdom through the right to a private life, and in Canada through the right to liberty and security of the person.[220] The right to life has also been found to be engaged in Canada and New Zealand, where the absence of VAD laws may force a person to commit suicide earlier than he or she otherwise would.

However, courts are divided as to their assessment of whether this restriction of human rights is justified. In Canada, the Supreme Court has authoritatively declared that an absolute prohibition on VAD cannot be justified as demonstrably necessary to protect the lives of vulnerable people. England and New Zealand do not have the same certainty arising from a unanimous pronouncement of their final appellate court.[221] But courts in

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illness. There was also evidence that some of these took their lives early, before they reached a point where they might not be able to do so: *Seales v Attorney-General* [2015] 3 NZLR 556 [51]-[52].

217 The 'right to life' in the *New Zealand Bill of Rights Act 1990* (NZ) is subject to the same caveat as the *Canadian Charter of Rights and Freedoms*, s 7, upholding laws derogating from that right which are in accordance with the 'principles of fundamental justice'. Collins J imported the factors used in Canada to assess whether a law is inconsistent with the 'principles of fundamental justice': namely, arbitrariness, overbreadth and gross disproportionality: *Seales v Attorney-General* [2015] 3 NZLR 556 [169]-[173].

218 *Seales v Attorney-General* [2015] 3 NZLR 556 [132].

219 *Seales v Attorney-General* [2015] 3 NZLR 556 [184]-[186].

220 This right is part of the composite right to 'life, liberty and security of the person': *Canadian Charter of Rights and Freedoms*, s 7.

221 An opportunity to do so was presented in *Nicklinson*, and again in *Conway*, but was passed up on both occasions. In *R (on the application of Nicklinson) v Ministry of Justice* [2015] AC 657, this was due to deference to Parliament, which had a Bill concerning assisted dying currently before it. The UK Supreme Court refused leave to appeal from the judgment of the Court of Appeal in *Conway*, 'not without some reluctance', because they considered the prospects of success were not sufficient to justify giving leave to appeal: *R (on the application of Conway) v Secretary of State for Justice* [2018] UKSC (27 November 2018). This

those countries have considered that the legislative purpose might not be solely the protection of vulnerable people, but also the protection of the value of all human life. In those circumstances, a blanket prohibition on VAD is more likely to be considered reasonable and necessary, justifying the obvious restriction on the autonomy rights of suffering people wishing to access assistance to die.

IMPLICATIONS FOR AUSTRALIA

[11.220] As reflected in the above examination, human rights jurisprudence is evolving and the courts are increasingly being used as a vehicle through which to challenge legal prohibitions on providing VAD. As Australia grapples with ongoing calls to reform the law to permit VAD, it is timely to consider what role, if any, human rights arguments can play in these debates. Four observations are proffered in this regard.

Human rights do not provide 'the answer'

[11.230] The first observation is that human rights arguments do not provide 'the answer' as to whether VAD should be lawful or not. The previous section highlighted some of the challenges encountered when using human rights instruments as a mechanism to drive law reform. One is that the rights generally contained in human rights instruments are 'imprecise terms', the interpretation of which will 'frequently involve an engagement with moral discourse'.[222] As has been seen, what is required by these human rights, in terms of permitting or prohibiting VAD, is the subject of judicial disagreement.[223] Further, rights not being absolute, they are subject to justified limitations in furtherance of a legitimate public purpose. The issue of the justification or proportionality of infringements on rights to a legitimate legislative objective has been the subject of significant analysis and discussion in the cases considered above, and it has been shown that different people can draw different conclusions on such matters.

The inability of human rights to dictate a particular position was recognised in Victoria when Parliament considered the introduction of VAD laws. For example, the Ministerial Advisory Panel noted that in England the right to life was held not to include the right to choose the manner of one's death, whereas the right to life was not held to prevent the legalisation of VAD

may indicate approval of the reasoning of the Court of Appeal, or perhaps some deficiency in the particular circumstances of Conway's case which rendered it not a suitable vehicle to authoritatively determine the issue.

222 Zdenkowski, n 2.

223 Rights talk is also the subject of considerable academic, legal and philosophical disagreement. The main arguments on both sides, and the problems with rights discourse, are succinctly summarised in Penney Lewis, 'Rights Discourse and Assisted Suicide', (2001) 27 *American Journal of Law & Medicine* 45.

in Canada.[224] The then Victorian Health Minister, Hon Jill Hennessy, also observed that in her view, the VAD Bill did not limit the right to life, but noted that others would take the opposite view.[225] This sort of radical indeterminacy, where the same human right can be used to justify diametrically opposed conclusions, suggests that at least some human rights have limited utility in determining the shape of the law.

These sentiments were echoed by the Australian Human Rights Commission following a review of the human rights relevant to VAD. The Commission concluded:

> An analysis of international human rights law relevant to the practice of voluntary euthanasia does not lead to 'the' answer. Rather it reveals a balancing of rights, the appropriate balance of which may be subject to competing views. … there is no one identifiable right that necessarily requires the legalisation of voluntary euthanasia, nor is there one identifiable right that prevents its legalisation, provided stringent safeguards are instituted.[226]

The Commission concluded that:

> … from a human rights perspective, the option exists to support legalisation of voluntary euthanasia practices provided that sufficient safeguards are put in place to prevent 'arbitrary' (including discriminatory) deprivations of life.[227]

Limitations on the influence of human rights at the Commonwealth level

[11.240] The second observation is that an obvious limitation on the potential influence of human rights in Australia is that there is no national Bill of rights or other general human rights legislation.[228] Australia has ratified the ICCPR and the *International Covenant on Economic, Social and Cultural Rights*, and their provisions are legally binding on Australia in international law. However, they are not enforceable in domestic law unless

224 Victorian Government, *Ministerial Advisory Panel on Voluntary Assisted Dying* (Final Report, 21 July 2017) 212. The right to life was examined in detail by Zdenkowski, who concluded it was unclear whether the right was mandatory and therefore inalienable, or discretionary and thus able to be waived: Zdenkowski, n 2, 13-15.

225 Victoria, *Parliamentary Debates*, Legislative Assembly, 21 September 2017, 2944 (Jill Hennessy MP).

226 Australian Human Rights Commission, n 65, 34-35.

227 Australian Human Rights Commission, n 65, 35.

228 The Commonwealth has enacted legislation to give effect to some international human rights, but these have been in specific areas such as sex, race, disability and age discrimination: *Racial Discrimination Act 1975* (Cth); *Sex Discrimination Act* 1984 (Cth); *Disability Discrimination Act 1992* (Cth); *Age Discrimination Act 2004* (Cth). The ICCPR is scheduled to the *Australian Human Rights Commission Act 1986* (Cth), but does not have the force of domestic law.

and until Parliament specifically legislates to give effect to some or all of those rights.[229]

Further, Australia has not specifically enacted legislation dealing with the right to life or the right to privacy in the sense discussed in this chapter.[230] Any case alleging that Australian laws prohibiting VAD infringe upon the right to life (such as was made in *Seales* or *Carter*) or the right to privacy (as was argued in *Nicklinson* and *Conway*) can only be brought before the UN Human Rights Committee via an individual communication under the *First Optional Protocol to the ICCPR*.[231] This is not a particularly effective remedy, given the process of making an individual communication to the Committee takes years, and the Committee has no fact-finding capacity, cannot conduct oral hearings and must proceed on the basis of the evidence contained in written submissions.[232] Further, the only outcome of this process is that the Committee publishes its views. Although these are an authoritative interpretation of the treaty,[233] they are not legally binding on States Parties and do not result in a domestically enforceable remedy for the individual complainant.[234] In some cases, however, international criticism of Australia may be effective in exerting political pressure towards law reform.[235]

Finally, the provisions of the *Disability Discrimination Act 1992* (Cth) do not appear broad enough to support equality arguments of the kind made in *Carter*, alleging that criminalising VAD indirectly discriminates against persons with disabilities who wish to end their lives.[236]

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229 International law can be relevant to clarify the interpretation of the common law (*R v Dietrich* (1992) 177 CLR 292, 305) or statute (*Kioa v West* (1986) 60 ALJR 113, 120, 147; *Minister of State for Immigration & Ethnic Affairs v Teoh* (1995) 183 CLR 273, 286-287) where ambiguity exists.

230 The *Privacy Act 1988* (Cth) is restricted to information privacy, and does not concern personal privacy or self-determination in medical decision-making.

231 Adopted and opened for signature, ratification and accession by General Assembly resolution 2200A (XXI) of 16 December 1966. Entry into force 23 March 1976, in accordance with Art 9.

232 Bantekas and Oette, n 66, 217.

233 Human Rights Committee, *General Comment 33: The Obligations of States Parties under the Optional Protocol to the International Covenant on Civil and Political Rights*, UN Doc CCPR/C/GC/33/CRP.3 (25 August 2008) [13].

234 It is worth noting that the cases brought under the *Human Rights Act 1998* (UK) and the *New Zealand Bill of Rights Act 1990* (NZ) also do not result in any remedy other than a declaration of incompatibility, and that the main purpose of such proceedings is to bring political pressure to bear to effect legislative change to bring legislation into line with human rights.

235 As occurred in the case of Nicholas Toonen's complaint against Tasmania's laws criminalising consensual homosexual activity: *Toonen v Australia (Decision)* (Human Rights Committee) Case No 488/1992, 31 March 1994.

236 See Divs 1 and 2 of Pt 2 of the *Disability Discrimination Act 1992* (Cth), especially s 24. The *Disability Discrimination Act 1992* (Cth) is focused on acts of discrimination in employment or in specific areas of social life, the most relevant in relation to assisted dying being access to goods and services.

Limitations on the influence of human rights at the state and territory level

[11.250] Given the limited legislative protection of human rights federally, any impact of human rights legislation is most likely to occur at the state and territory level. Currently, three Australian jurisdictions – Victoria,[237] the ACT[238] and Queensland[239] – have statutory Bills of rights. However, such legislation is less likely to influence debates about VAD in the way that the national and international human rights instruments described above have in other countries, for two reasons.

The first reason is that the scope of the rights to privacy and liberty and security of the person recognised in the Victorian, ACT and Queensland human rights legislation is narrower than those rights as defined in Canadian or English law, although the right to life is stated in materially identical terms and may be broad enough to sustain a human rights argument relating to VAD.

The *Charter of Human Rights and Responsibilities Act 2006* (Vic) (the *Victorian Charter*), the *Human Rights Act 2004* (ACT) and the *Human Rights Act 2019* (Qld) are all closely modelled on the ICCPR. However, there are significant differences between the human rights contained in the ICCPR and the Victorian, ACT and Queensland Acts, and the human rights enshrined in the *Canadian Charter* and ECHR. For example, the right to respect for one's private and family life contained in the ECHR[240] is broader than the corresponding right not to have one's privacy 'unlawfully or arbitrarily interfered with'.[241] Thus, the right to privacy in Australian laws does not seem to protect self-determination in the same way as the English right to respect for one's private life. It is a much lower threshold to assert that a law prohibiting VAD constitutes an interference with one's private life than to successfully argue that this interference is 'unlawful' or 'arbitrary'. In *Nicklinson* and *Carter*, the Supreme Courts of both England and Canada concluded that the relevant law in those countries was not arbitrary,[242] although in Canada the blanket ban on VAD was held to be disproportionate.

237 *Charter of Rights and Responsibilities Act 2006* (Vic).

238 *Human Rights Act 2004* (ACT).

239 *Human Rights Act 2019* (Qld).

240 The *Convention for the Protection of Human Rights and Fundamental Freedoms*, Art 8, implemented in domestic law by *Human Rights Act 1998* (UK), s 1.

241 *Charter of Rights and Responsibilities Act 2006* (Vic), s 13; *Human Rights Act 2004* (ACT), s 12; *Human Rights Act 2019* (Qld), s 25.

242 The statement of the ECtHR in *Pretty v United Kingdom* (2002) 35 EHRR 1 [76] that a prohibition on VAD was not arbitrary was quoted with approval in *R (on the application of Nicklinson) v Ministry of Justice* [2015] AC 657 [32] (Lord Neuberger), [156] (Lord Mance), [214] (Lord Sumption); *Carter v Canada (A-G)* [2015] 1 SCR 331 [83]-[84].

Further, the right to liberty and security of the person contained in the ICCPR[243] and reproduced in the Victorian, ACT and Queensland Acts[244] does not seem as broad as the Canadian counterpart.[245] The numerous subparagraphs defining the right appear focused on freedom from arbitrary arrest and detention,[246] similar to the scope of Art 9 of the ICCPR, rather than protecting personal autonomy in decision-making as the Canadian right does.[247]

It is possible, however, that the right to life[248] could be interpreted in a way similar to that in *Seales* and *Carter*, and a State prohibition on assisted suicide may be perceived as depriving persons with a disability or with progressive degenerative diseases of some life, if they feel constrained to commit suicide prematurely, while they still retain bodily control.[249]

A second limitation is that there are no enforceable legal consequences that flow from infringing human rights legislation enacted at state or territory level. Even if it could be argued that prohibiting VAD was in breach of the legislation and infringed a right, the remedy provided is limited. In the ACT, Victoria and Queensland, as is the case in the United Kingdom and New Zealand,[250] courts can only make a declaration of incompatibility.[251] This

243 The ICCPR, Art 9 states that 'Everyone has the right to liberty and security of the person'. It then goes on immediately to discuss arbitrary arrest, detention and deprivation of liberty.

244 *Charter of Rights and Responsibilities Act 2006* (Vic), s 21; *Human Rights Act 2004* (ACT), s 18; *Human Rights Act 2019* (Qld), s 29.

245 The *Canadian Charter of Rights and Freedoms*, s 7 enshrines the 'right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice'. There is no mention of arbitrary arrest, detention or deprivation of liberty.

246 *Charter of Rights and Responsibilities Act 2006* (Vic), s 21(2)-(8); *Human Rights Act 2004* (ACT), s 18(2)-(8); *Human Rights Act 2019* (Qld), s 29(2)-(8). That the scope of the Victorian right is more limited than its Canadian counterpart was expressly recognised by the Ministerial Advisory Panel. The panel considered the right is limited to arbitrary arrest and detention, and of limited applicability in the context of VAD: Victorian Government, n 224, 215.

247 See discussion of the Right to Liberty and Security of the Person in [11.70].

248 *Charter of Rights and Responsibilities Act 2006* (Vic), s 9; *Human Rights Act 2004* (ACT), s 9; *Human Rights Act 2019* (Qld), s 16.

249 *Seales v Attorney-General* [2015] 3 NZLR 556 [29]; *Carter v Canada (Attorney General)* [2012] BCSC 886 [1322]; *Carter v Canada (A-G)* [2015] 1 SCR 331 [57]-[58]. See generally the Right to Life in [11.60].

250 See *Human Rights Act 1998* (UK), s 4. In New Zealand, there does not appear to be an express statutory procedure for a declaration of incompatibility or inconsistency, but it appears to be implied in the provision stating that if any law is inconsistent with human rights, a court may not hold it to be invalid, impliedly repealed or revoked, or decline to apply it: *New Zealand Bill of Rights Act 1990* (NZ), s 4. In the United Kingdom, the requirement to interpret legislation consistently with human rights 'so far as it is possible to do so' (*Human Rights Act 1998* (UK), s 3) has accorded the courts flexibility to provide effective remedies to complainants in several cases.

251 In Victoria, the Supreme Court may make a 'declaration of inconsistent interpretation' if it is of the opinion that a legislative provision cannot be interpreted consistently with

does not result in the law being declared invalid or give an individual a legal right or civil cause of action.[252] It merely requires Parliament to consider the issue.[253] As such, it provides no direct legal remedy to a complainant. This can be contrasted, for example, with the situation in Canada, where Charter challenges may result in a remedy for an individual whose rights have been violated,[254] or may result in a court order that a law which infringes a person's Charter rights is not valid.[255]

Values, rather than human rights, driving reform

[11.260] A final reflection is that, although Victoria has a statutory Bill of rights, and this had some relevance to the Government's decision to implement a VAD law and its design, human rights were arguably not the primary driver of reform. The guiding principles[256] outlined by the Ministerial Advisory Panel,[257] and enshrined in the VAD legislation, undergirded the reform to a much more significant extent. This observation is underscored by the fact that Western Australia, a state without a statutory Bill of rights, in 2019, also legislated to permit VAD, adopting a broadly equivalent legal framework and citing substantially identical guiding principles.[258]

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a human right protected in the *Victorian Charter*. But this declaration does not affect the validity of the law in question: *Charter of Rights and Responsibilities Act 2006* (Vic), s 36. In the ACT and Queensland, this is known as a 'declaration of incompatibility': *Human Rights Act 2004* (ACT), s 32; *Human Rights Act 2019* (Qld), s 53.

252 *Charter of Rights and Responsibilities Act 2006* (Vic), s 36(5); *Human Rights Act 2004* (ACT), s 32(3); *Human Rights Act 2019* (Qld), s 54.

253 In Victoria and Queensland, the responsible Minister must prepare a written response to the declaration of inconsistent interpretation, and table it in Parliament within six months: *Charter of Rights and Responsibilities Act 2006* (Vic), s 37; *Human Rights Act 2019* (Qld), s 56. In the ACT, this is the duty of the Attorney-General: *Human Rights Act 2004* (ACT), s 33.

254 *Canadian Charter of Rights and Freedoms*, s 24.

255 *Canada Act 1982* (UK), c 11, Sch B, s 52.

256 These principles are valuing every human life equally; respecting autonomy; supporting informed decision-making; providing quality care that minimises suffering and maximises quality of life; supporting therapeutic relationships; encouraging open discussions about dying, death and people's preferences; supporting conversations with health professionals and family about treatment and care preferences; promoting genuine choices; protecting individuals from abuse; and respecting diversity of beliefs and values, including among health practitioners: *Voluntary Assisted Dying Act 2017* (Vic), s 5(1). See also the Victorian Government, n 224.

257 Victorian Government, n 224. The Panel comprised seven experts from a range of disciplines: a neurosurgeon, three palliative care professionals, a lawyer, a disability advocate and a health consumer advocate: O'Connor et al, n 20, 623.

258 The *Voluntary Assisted Dying Act 2019* (WA), s 4 includes 11 principles rather than 10. The 11th is that 'a person who is a regional resident is entitled to the same level of access to voluntary assisted dying as a person who lives in the metropolitan region', a consideration that is of more significance in Western Australia than in Victoria.

Human rights were considered by the Ministerial Advisory Panel,[259] as evidenced in Appendix 2 to the Panel's Report which sets out its view as to how the human rights contained in the Charter interact with the VAD law it proposed.[260] The Health Minister, the Hon Jill Hennessy, also provided a detailed statement of compatibility with human rights when introducing the VAD Bill into Parliament.[261] Seven rights were listed as relevant to the introduction of VAD.[262] Two of these rights – the right to liberty and security of the person, and the right to freedom from torture and other cruel, inhuman or degrading treatment – were dismissed by the Panel as inapplicable, or not engaged by the VAD law.[263] A further three (the rights to life, privacy and equality) were the subject of detailed consideration as to why the limits on the enjoyment of rights contained in the VAD law were demonstrably justified and hence appropriate.[264]

However, the guiding principles articulated in the legislation itself, rather than human rights, were the driving force behind the introduction of VAD laws in Victoria. The guiding principles were repeatedly referred to throughout the Panel's Report when explaining its many recommendations.[265]

259 The Panel noted that it had taken into account the human rights protected in the *Charter of Rights and Responsibilities Act 2006* (Vic), and 'carefully considered how the relevant rights can be promoted': Victorian Government, n 224, 43. See also O'Connor et al, n 20, 623. Indeed, the authors, who were the Ministerial Advisory Panel, suggest that their review was strongly guided by Victorian human rights legislation.

260 Victorian Government, n 224.

261 Victoria, n 225, 2943-2949.

262 Seven human rights were specifically listed as being relevant to the VAD legislation. These were the rights to: equality; life; protection from torture and cruel, inhuman or degrading treatment; privacy and reputation; freedom of thought, conscience, religion and belief; protection of the best interests of the child; and liberty and security of person: Victorian Government, n 224, 43, Appendix 2.

263 The Panel referred to the right to liberty and security of the person, which in Victoria protects a person from arbitrary arrest and detention, rather than enshrining any general principle of personal autonomy: Victorian Government, n 224, 215. But compare the Minister's second reading speech, where she accepts that the right to liberty and security encompasses the principle of autonomy: Victoria, n 225, 2945. The Minister also stated that the right to protection from torture and cruel, inhuman or degrading treatment was not engaged by the VAD law: Victoria, n 225, 2946. Although the Panel discussed the requirement that a person provide voluntary consent to medical treatment as an aspect of the latter right (Victorian Government, n 224, 213), this does not detract from the Minister's statement.

264 Much of the Ministerial Advisory Panel's discussion of human rights was devoted to explaining the Panel's view as to why limitations on these rights were justified. There was considerable discussion of this in relation to the eligibility criteria limiting the right to equality before the law: Victorian Government, n 224; Victoria, n 225, 2947-2949. There was also discussion of whether the stringent regime of safeguards limited the enjoyment of the right to life (Victorian Government, n 224, 213) and limits on the right to privacy by the information collection provisions (Victorian Government, n 224, 213-214; Victoria, n 225, 2946).

265 These guiding principles also appeared in the final Victorian legislation: *Voluntary Assisted Dying Act 2017* (Vic), s 5. For a consideration of the extent to which the Victorian legislation

By contrast, human rights were specifically referred to in justifying only two recommendations.[266] Members of the Panel and the Minister for Health stated that the guiding principles are based on the human rights contained in the *Victorian Charter*[267] and there is certainly some overlap between those human rights and the guiding principles, particularly the right to life and the freedom of thought, conscience and belief. But key themes in the guiding principles, such as the provision of high-quality care in the context of open and caring therapeutic relationships, which informed five of the guiding principles,[268] do not find expression in the *Victorian Charter*.[269] And other highly significant guiding principles, such as respect for autonomy, promoting genuine choices, and safeguarding the vulnerable and the community, are at best obliquely based on the human rights set out in the Charter.[270] Thus, while human rights were considered by the Panel and the Government (as they should be), the primary drivers in deciding to change the law and in formulating the shape of the law were those wider guiding principles.

Of note is that Western Australia, which does not have human rights legislation, adopted a similar approach in its reform work, having identified

reflected the stated policy goals of the legislation, see Ben White, Katrine Del Villar, Eliana Close and Lindy Willmott, 'Does the Voluntary Assisted Dying Act 2017 (Vic) Reflect Its Stated Policy Goals?', (2020) 43(2) *University of New South Wales Law Journal* 417.

266 These were allowing people to access VAD where they suffer from an incurable condition, whether or not they have exhausted all other available treatment options was justified on the basis that to do otherwise would infringe human rights (Victorian Government, n 224, 67), and the provisions allowing medical practitioners freedom to conscientiously object to participating in VAD were justified by reference to the right to freedom of thought, conscience, religion and belief: Victorian Government, n 224, 109.

267 O'Connor et al, n 20, 625. The Minister also claimed that the Panel used the Charter as a framework for formulating the VAD model and the guiding principles: Victoria, n 225, 2943.

268 These principles are supporting informed decision-making; providing quality care that minimises suffering and maximises quality of life; supporting therapeutic relationships; encouraging open discussions about dying, death and people's preferences; and supporting conversations with health professionals and family about treatment and care preferences.

269 The *Charter of Rights and Responsibilities Act 2006* (Vic) does not contain a 'right to health' or a 'right to healthcare' or any equivalent.

270 The Panel observed that the right to liberty and security of the person does not broadly protect personal autonomy: Victorian Government, n 224, 215. It is also unclear the extent to which personal autonomy is contained in the right to privacy. Although the Panel is of the view that the right to privacy and protection from unlawful and arbitrary interference with a person's physical integrity is linked to human dignity and personal autonomy, most of its discussion of the right to privacy is centred around the collection of personal information: Victorian Government, n 224, 213-214. The Minister's statement of compatibility on introducing the VAD Bill also focuses exclusively on information privacy when discussing the privacy and reputation rights contained in *Charter of Rights and Responsibilities Act 2006* (Vic), s 13.

and adopted a series of principles or values to guide its approach.[271] These principles are also enshrined in the *VAD Act* (WA). A focus on values or guiding principles does not necessarily mean human rights are neglected. For example, both Victoria's and Western Australia's principles or values included important human rights domains such as respecting human life, respecting autonomy, and equal treatment. However, in discussions to date about VAD reform in Australia, wider principles or values have been given greater prominence than human rights considerations.

CONCLUSION

[11.270] Through their parliamentary processes, Australians have been debating whether or not to enact VAD legislation for close to three decades. VAD, and whether it should be permitted, is one of the biggest moral dilemmas of our time, not only in Australia but internationally. Enacting legislation to enable a person to receive assistance to end their life raises extraordinarily complex issues and represents a profound challenge to our society.

There are a range of likely explanations as to why reform is occurring now despite decades of failed legislative attempts. It may be a combination of factors such as the increasing legalisation of VAD around the world, the increasing volume of social science evidence now available concerning the ability of legislative safeguards to protect vulnerable individuals or the sustained level of public support and media agitation for change.[272] But, at least in Australia, human rights discourse does not appear to be driving that march forward.

Zdenkowski's observations about the role of human rights, that were made in 1996, appear to be equally relevant in Australia in 2020, more than 20 years later. He stated:

> Political and moral judgments in relation to voluntary euthanasia are not ultimately capable of resolution exclusively by reference to international human rights standards. Probable legal conformity with human rights standards (for example Art 6(1) ICCPR) is not determinative of the moral or political appropriateness of a particular law such as the [*Rights of the Terminally Ill Act 1995* (NT)]. HREOC [273] can advise as to the likely human rights implications of such a measure. But the final political and moral judgment (which necessarily includes an assessment of whether it is possible to guarantee via safeguards

271 Two of the authors have also done this in outlining a set of values they consider should guide decisions about VAD reform: Willmott and White, n 15, 479-510. The authors have also drafted a Voluntary Assisted Dying Bill which seeks to reflect these values: Ben White and Lindy Willmott, 'A Model Voluntary Assisted Dying Bill', (2019) 7(2) *Griffith Journal of Law and Human Dignity* 1.

272 For a discussion of this, see White and Willmott, n 3.

273 The Human Rights and Equal Opportunity Commission, now the Australian Human Rights Commission.

> that a statutory scheme authorising limited active voluntary euthanasia will never be abused) must be one for the legislature.[274]

Thus, it is unlikely that a human rights analysis will provide the answer to the 'wicked question' of whether a person should be entitled to assistance to die in some circumstances. That said, human rights continue to be important considerations in debates about VAD reform. The process of identifying relevant rights and then considering whether it is justifiable to limit them for a legitimate social purpose promotes rigour in deliberations about the future direction of the law. It also ensures that the rights of people affected – including patients, health professionals and the vulnerable – are at the forefront of these debates and the subject of careful consideration.

ADDITIONAL RESOURCES

Penney Lewis, 'Rights Discourse and Assisted Suicide', (2001) 27 *American Journal of Law & Medicine* 45.

Stevie Martin, 'A Human Rights Perspective of Assisted Suicide: Accounting for Disparate Jurisprudence', (2018) 26(1) *Medical Law Review* 98.

Danuta Mendelson and Mirko Bagaric, 'Assisted Suicide through the Prism of the Right to Life', (2013) 36 *International Journal of Law and Psychiatry* 406.

Antje Pedain, 'The Human Rights Dimension of the *Diane Pretty* Case', (2003) 62(1) *Cambridge Law Journal* 181.

Elizabeth Wicks, 'The Law and Ethics of Assisted Dying: Is There a Right to Die?', in Elizabeth Wicks (ed), *Human Rights and Healthcare* (Hart Publishing, London, 2007).

Lindy Willmott and Ben White, 'Assisted Dying in Australia: A Values-Based Model for Reform', in Ian Freckelton and Kerry Petersen (eds), *Tensions and Traumas in Health Law* (Federation Press, Sydney, 2017).

274 Zdenkowski, n 2, 18.