

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

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Eligibility criteria in voluntary assisted dying legislation determine access to assistance to die. This article 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 article 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 article 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 has access to VAD and in what circumstances. The primary mechanism to control access is the eligibility criteria in VAD legislation. In the first article in this two-part series,¹ we undertook a critical and comparative

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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*')² drafted for consideration by other Australian states and recommended by the Queensland Parliamentary Inquiry considering VAD as the proposed basis for reform.³ The international models were Oregon's *Death with Dignity Act 1994* ('*Oregon Act*')⁴ and Canada's *Criminal Code* ('*Canadian Criminal Code*').⁵ A comparative analysis of these criteria across the five selected regimes

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- 1 Ben P White et al, 'Comparative and Critical Analysis of Key Eligibility Criteria for Voluntary Assisted Dying under Five Legal Frameworks' (2021) 44(4) *University of New South Wales Law Journal* 1663 ('Comparative and Critical Analysis of Key Eligibility Criteria for VAD').
- 2 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/128753/9/128753.pdf>>. 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').
- 3 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*'). After this article was submitted for publication, voluntary assisted dying ('VAD') laws were enacted in Queensland, as well as in Tasmania and South Australia: *Voluntary Assisted Dying Act 2021* (Qld); *End-of-Life-Choices (Voluntary Assisted Dying) Act 2021* (Tas); *Voluntary Assisted Dying Act 2021* (SA). In New South Wales, the Voluntary Assisted Dying Bill 2021 (NSW) has passed the Legislative Assembly and will be considered by the Legislative Council in 2022.
- 4 *Death with Dignity Act*, Or Rev Stat §§ 127.800–127.995 (1994) ('*Oregon Act*').
- 5 *Criminal Code*, RSC 1985, c C-46, ss 241.1–241.4 ('*Canadian Criminal Code*'). Until recently, the Canadian *Criminal Code* prohibited all forms of assisted dying. In 2015, the blanket prohibition was found to violate the Canadian *Charter of Rights and Freedoms* ('*Charter*') and was struck down by the Supreme Court of Canada in *Carter v Canada (Attorney General)* [2015] 1 SCR 331 ('*Carter*'). In 2016,

demonstrated many similarities but also significant differences in who would be eligible to access VAD. The article concluded with implications of these analyses from a regulatory perspective for designing VAD legislation.

This second article 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 article 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),⁶ motor neurone disease ('MND'), chronic obstructive pulmonary disease ('COPD'), chronic kidney disease ('CKD'), dementia (specifically Alzheimer's disease),⁷ 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 where data concerning VAD is available).⁸ Data from Oregon and Canada on deaths due to VAD demonstrate that the three most common underlying conditions are

the federal Parliament passed legislation (Bill C-14, *An Act to Amend the Criminal Code and to Make Related Amendments to Other Acts (Medical Assistance in Dying)*, 1st Sess, 42nd Parl, 2016 ('Bill C-14')) to amend the Canadian *Criminal Code* to make it consistent with the *Charter* and provide a regulatory framework for medical assistance in dying ('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 Procureur Général du Canada* [2019] QCCS 3792 ('Truchon'). In 2021, the Canadian *Criminal Code* was further amended through Bill C-7, *An Act to Amend the Criminal Code (Medical Assistance in Dying)*, 2nd Sess, 43rd Parl, 2021 (as passed by the House of Commons 17 March 2021) ('Bill C-7'). Amendments of particular relevance for this article include: removing the original eligibility criterion 'natural death has become reasonably foreseeable': see Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(2)(d), as enacted; 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): Bill C-7, 2nd Sess, 43rd Parl, 2021, cls 1(2), 1(2.1) and 6 (as passed by the House of Commons 17 March 2021); 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 to a written arrangement with their VAD provider to provide VAD after they lose decision-making capacity ('final consent waiver'): Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(3.2); Bill C-7, 2nd Sess, 43rd Parl, 2021, cl 1(3.2) (as passed by the House of Commons 17 March 2021).

6 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.

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

8 The *Voluntary Assisted Dying Act 2019* (WA) ('*WA Act*') commenced on 1 July 2021, so no data is currently available. The Model Bill (n 2) is not operational.

cancer,⁹ neurological conditions (including MND)¹⁰ and respiratory conditions (such as COPD).¹¹ There is 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.¹² Anecdotal reports about the Victorian system also suggest that cancer, neurological disease and respiratory conditions are the most prevalent conditions.¹³ However, considering only conditions for which VAD is commonly sought would not explore the potential boundaries of the legislation for other 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, Belgium¹⁴ and Canada.¹⁵ We also included medical conditions discussed in the VAD literature,¹⁶

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- 9 In Oregon in 2019, 68.1% 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*’).
- 10 In Oregon in 2019, neurological disease accounted for 13.8% of VAD deaths, with 10.1% from amyotrophic lateral sclerosis, a form of Motor Neurone Disease (‘MND’), alone: *Oregon Data Summary* (n 9) 10–11. In Canada in 2019, 10.4% of VAD deaths involved people with neurological conditions: *Canadian First Annual Report* (n 9) 22.
- 11 In Oregon in 2019, 7.4% of VAD deaths involved people with respiratory disease: *Oregon Data Summary* (n 9) 10–11. Canada’s statistics indicate 10.8% of VAD deaths involved respiratory conditions: *Canadian First Annual Report* (n 9) 22.
- 12 Voluntary Assisted Dying Review Board (Vic), *Report of Operations: January to June 2020* (Report, August 2020) 10. This report 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 breakdown 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 Voluntary Assisted Dying Review Board (Vic)’s VAD data is not discussed further.
- 13 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* (Web Page, 16 June 2020) 3 <https://www.dwdv.org.au/wp-content/uploads/2020/07/One_Year_of_VAD-Dr_Cameron_McLaren.pdf>. Another Victorian general practitioner who has provided VAD states that after one year in operation, ‘[c]ancer 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>>.
- 14 As noted in the first article in this series, these jurisdictions are not included in this article 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 1).
- 15 Canada is one of the most permissive VAD regimes and a shared legal heritage makes Canada a natural comparator for Australia here.
- 16 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.

including those described as controversial, such as Alzheimer's disease¹⁷ and one kind of mental illness, anorexia.¹⁸ The resulting list, therefore, included not only typical 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. Part II 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). Part III then considers medical conditions for which access to VAD is either clearly not permitted or very unlikely under the Australian models. Examples include Alzheimer's and Huntington's diseases. Part IV explores similarities and differences across models and considers the effects of differently

See also Jocelyn Downie and Jennifer A Chandler, *Interpreting Canada's Medical Assistance in Dying Legislation* (Report, Institute for Research on Public Policy, 1 March 2018) ('IRPP Report').

- 17 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* 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', *Policy Options* (online, 21 April 2021) <<https://policyoptions.irpp.org/magazines/april-2021/for-people-with-dementia-changes-in-maid-law-offer-new-hope/>>; Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(3.2).
- 18 VAD is permissible for people with mental illness who meet the other eligibility criteria in the Netherlands and Belgium: Scott YH 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 17). The use of VAD for mental illness remains controversial: see, eg, 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*, RSC 1985, c C-46, 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, 2nd Sess, 43rd Parl, 2021, cl 6 (as passed by the House of Commons 17 March 2021) 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* (Web Page, 18 March 2021) <<https://www.canada.ca/en/health-canada/services/medical-assistance-dying.html>>.

drafted eligibility criteria. Parts V and VI discuss implications for regulators and policymakers designing VAD regulation.

This article, like the previous article, 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 article does not consider other criteria unrelated to medical conditions, such as age and residency, and presumes they are met. The article 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.¹⁹ Because 'suffering' is an individual experience, one person may experience the 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 article adopts terminology used in the *Victorian Act* (subsequently mirrored in the *WA Act* and Model Bill). VAD therefore includes both 'self-administration'²⁰ and 'practitioner administration'.²¹ '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 has in only considering 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 article 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 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.

19 See, eg, *Victorian Act 2017* (Vic) s 9(1)(d)(iv); *WA Act 2019* (WA) s 16(1)(c)(iii).

20 The person takes the prescribed medication themselves; sometimes this is called physician-assisted suicide or physician-assisted dying.

21 The person is administered the medication by a doctor, or nurse practitioner in Western Australia or Canada; sometimes this is called voluntary euthanasia.

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.²² The severity of the disease varies depending on the extent to which it has spread. Stage I of the 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.²³ 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.²⁴ Treatment options depend on the extent of disease. The majority of people with extensive metastatic disease are diagnosed as incurable²⁵ and have a median survival of five to six months with supportive care²⁶ or 11 months with multi-drug chemotherapy.²⁷

2 Victoria

To be eligible under the *Victorian Act*, a person's colorectal cancer must be incurable, advanced and progressive, with a prognosis of six months or less.²⁸ 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.

22 Australian Government, Australian Institute of Health and Welfare, *Cancer in Australia 2019* (Report, Cancer Series No 119, Catalogue No CAN 123, 21 March 2019) vii.

23 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>>.

24 Ibid.

25 Yvette HM Claassen et al, 'Survival Differences with Immediate Versus Delayed Chemotherapy for Asymptomatic Incurable Metastatic Colorectal Cancer' (2018) 11 *Cochrane Database of Systematic Reviews* CD012326:1–33.

26 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, 754.

27 Ibid. See also 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, reporting a median 3.5 month increase in survival following treatment with a different combination of active agents: at 1209.

28 *Victorian Act 2017* (Vic) ss 9(1)(d)(i)–(iii).

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 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* for colorectal cancer will be similar to the *Victorian Act*. One key difference is that the *WA Act* does not require the cancer be incurable.²⁹ 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 will be similar to the *Victorian Act*, 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 is expected to cause death,³⁰ 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.³¹ A conclusion that 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.³² Colorectal cancer can meet the requirements to be a terminal disease in the *Oregon Act*: that is, incurable and irreversible, and expected (within reasonable medical judgment) to produce death within six months.³³

29 *WA Act 2019* (WA) ss 16(1)(c)(i)–(ii).

30 Model Bill (n 2) cl 9(e).

31 *Ibid* cl 9(e)(i)–(ii).

32 *Oregon Data Summary* (n 9) 10.

33 *Oregon Act*, Or Rev Stat § 127.800(12) (1994).

6 Canada

The Canadian *Criminal Code*³⁴ allows access to VAD for colorectal cancer³⁵ at an earlier stage than the other frameworks. Under the *Criminal Code*, the cancer must be ‘serious and incurable’,³⁶ 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.³⁷ 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 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.³⁸ 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 Act*, *WA Act* and *Oregon Act*, 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, as there is no six months prognosis requirement. The Canadian *Criminal Code*³⁹ 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 holistically rather than being limited only to that caused by the specific condition (here colorectal cancer).

34 Canadian *Criminal Code*, RSC 1985, c C-46, ss 241.1–241.2.

35 Note that cancer is the most common underlying condition for individuals who receive VAD in Canada: *Canadian First Annual Report* (n 9) 22.

36 Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(2)(a).

37 *IRPP Report* (n 16) 16–19. See also White et al, ‘Comparative and Critical Analysis of Key Eligibility Criteria for VAD’ (n 1) Part II(F)(2)(a).

38 See, eg, Legal and Social Issues Committee, Parliament of Victoria, *Inquiry into End of Life Choices* (Final Report, June 2016) 199–202; Department of Health and Human Services (Vic), *Ministerial Advisory Panel on Voluntary Assisted Dying* (Final Report, 31 July 2017) 12, 78 (‘MAP Report’).

39 Canadian *Criminal Code*, RSC 1985, c C-46.

B Motor Neurone Disease

1 Nature of Condition

MND⁴⁰ comprises a rare group of diseases where the nerve cells that control the body's muscles degenerate and subsequently die.⁴¹ It has a prevalence of 8.7 per 100,000 people in Australia.⁴² MND causes progressive loss of innervation to muscle groups which leads to weakness, spasticity and wasting.⁴³ 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 die within thirty months and less than 20% survive beyond five years from the onset of symptoms.⁴⁴ Average life expectancy is two and a half years.⁴⁵

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.⁴⁶

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).⁴⁷ A lack of capacity could preclude access in some cases, given executive function is sometimes impaired, and particularly when a person experiences frontotemporal dementia.

40 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 (Attorney-General)* [1993] 3 SCR 519; *Carter* [2015] 1 SCR 331 (Gloria Taylor); *R (Pretty) v Director of Public Prosecutions* [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 (Admin).

41 'What is Motor Neurone Disease (MND)?', *MND Australia* (Web Page, 2020) <<https://www.mndaustralia.org.au/mnd-connect/what-is-mnd/what-is-motor-neurone-disease-mnd>>.

42 Deloitte Access Economics, *Economic Analysis of Motor Neuron Disease in Australia* (Report, November 2015) 14 ('*Economic Analysis of MND*').

43 Matthew C Kiernan et al, 'Amyotrophic Lateral Sclerosis' (2011) 377(9769) *Lancet* 942, 944, 948.

44 Kevin Talbot, 'Motor Neuron Disease: The Bare Essentials' (2009) 9(5) *Practical Neurology* 303, 303.

45 *Economic Analysis of MND* (n 42) 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.

46 GM Ringholz et al, 'Prevalence and Patterns of Cognitive Impairment in Sporadic ALS' (2005) 65(4) *Neurology* 586.

47 *Victorian Act 2017* (Vic) s 9(4); *WA Act 2019* (WA) s 16(1)(c)(ii).

3 Model Bill

People with MND would also be eligible under the Model Bill. 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; 10.1% of all persons who died in 2019 under the Oregon scheme had the disease.⁴⁸ 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.⁴⁹ However, the category of persons who are eligible may be narrower in Oregon than in Victoria and Western Australia, as the person must be within six months of death rather than 12 months.⁵⁰

5 Canada

A person with MND can be eligible for VAD in Canada.⁵¹ MND meets the serious and incurable disease criterion on diagnosis.⁵² 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*⁵³ 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,⁵⁴ so this option of

48 *Oregon Data Summary* (n 9) 10–11.

49 *Oregon Act*, Or Rev Stat § 127.800(12) (1994).

50 *Ibid.*

51 The *Canadian First Annual Report* (n 9) 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.

52 *Canadian Criminal Code*, RSC 1985, c C-46, s 241.2(2)(a).

53 *Ibid* s 241.2(3.2). See also White et al, 'Comparative and Critical Analysis of Key Eligibility Criteria for VAD' (n 1) Part II(F)(1).

54 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

exercising the final consent waiver provision will be available to eligible persons with MND at risk of losing decision-making capacity.

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 six months of death, followed by Victoria and Western Australia with 12 months. The Model Bill 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

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.⁵⁵ It is the fifth leading cause of death in Australia for both men and women.⁵⁶ Increasing airway narrowing and lung destruction causes symptoms to worsen over time. The symptoms include breathlessness, coughing 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 respiratory function is so compromised that they lack sufficient oxygen, this may cause confusion and affect a person's decision-making capacity.⁵⁷

People can live for many years with the disease, but it does shorten life, particularly when the COPD is advanced.⁵⁸ Prognostication is incredibly difficult because the trajectory of COPD is 'chaotic',⁵⁹ with slow, chronic decline over time interspersed with acute exacerbations, any of which may cause death.⁶⁰

years': Canada, *Parliamentary Debates*, Senate, 1 June 2016, 1700 (Jane Philpott). See also Downie and Scallion (n 16) 48–9.

55 Global Initiative for Obstructive Lung Disease, *Pocket Guide to COPD Diagnosis, Management and Prevention: A Guide for Health Care Professionals* (Report, 2019) 2.

56 Australian Government, Australian Institute of Health and Welfare, *Deaths in Australia* (Web Report, 25 June 2021) <<https://www.aihw.gov.au/getmedia/743dd325-7e96-4674-bb87-9f77420a7ef5/Deaths-in-Australia.pdf.aspx?inline=true>>.

57 Fiona AHM Cleutjens et al, 'Domain-Specific Cognitive Impairment in Patients with COPD and Control Subjects' (2016) 12 *International Journal of Chronic Obstructive Pulmonary Disease* 1.

58 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 Chronic Obstructive Pulmonary Disease* 137.

59 Amanda Landers et al, 'Severe COPD and the Transition to a Palliative Approach' (2017) 13(4) *Breathe* 310, 311.

60 Ibid.

2 Victoria and Western Australia

COPD is incurable, 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 six months.⁶¹ 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.⁶²

3 Model Bill

A person with COPD could access VAD under the Model Bill. 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',⁶³ but it would be possible for a doctor to conclude that all eligibility criteria are met at an earlier point than under the *Victorian Act* or *WA Act*. 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 '[r]espiratory disease [eg, COPD]'.⁶⁴ 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.⁶⁵ 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.⁶⁶ Under the Canadian *Criminal Code*,⁶⁷ a person with COPD could satisfy the eligibility requirements to access VAD as it is a 'serious' and 'incurable' illness. Because there is no 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',⁶⁸

61 *Victorian Act 2017* (Vic) s 9(1)(d)(iii); *WA Act 2019* (WA) s 16(1)(c)(ii).

62 *Victorian Act 2017* (Vic) s 9(1)(c); *WA Act 2019* (WA) s 16(1)(d).

63 Model Bill (n 2) cl 9(e)(ii).

64 *Oregon Data Summary* (n 9) 11.

65 *Oregon Act*, Or Rev Stat § 127.800(12) (1994).

66 *Canadian First Annual Report* (n 9) 22.

67 Canadian *Criminal Code*, RSC 1985, c C-46, ss 241.2(1)–(2).

68 *Ibid* s 241.2(2)(b).

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 have lost capacity through the final consent waiver provision.⁶⁹

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

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 at least three months.⁷⁰ In most cases, CKD is irreversible, and therefore incurable.⁷¹ In Australia, CKD is estimated to contribute to 11% of all deaths with it being the underlying cause in 21% of those deaths.⁷²

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.⁷³ Patients with CKD are also susceptible to alterations in cognitive function, including stroke and dementia, and this may affect decision-making capacity.⁷⁴

69 Ibid s 241.2(3.2).

70 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, 19–24.

71 Ibid 19.

72 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>>.

73 Carol Mattson Porth and Glenn Maftin, *Pathophysiology: Concepts of Altered Health States* (Lippincott Williams and Wilkins, 8th ed, 2009) 859.

74 Ria Arnold et al, 'Neurological Complications in Chronic Kidney Disease' (2016) 5 *Journal of the Royal Society of Medicine Cardiovascular Disease* 1.

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.⁷⁵ Not all individuals with CKD will progress to end-stage kidney disease and for those that do, the progression is frequently non-linear.⁷⁶ This makes prognostication difficult.⁷⁷

2 Victoria and Western Australia

By the later stages of CKD, a person would have a medical condition that is ‘advanced and progressive’.⁷⁸ There are two challenging aspects under the *Victorian Act* and *WA Act*, however. First, because the disease’s trajectory varies, establishing a six-month prognosis may be difficult.⁷⁹ 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.⁸⁰

3 Model Bill

The absence of the prognosis requirement under the Model Bill 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.⁸¹ Capacity issues remain the same as under the *Victorian Act* and *WA Act*.⁸²

4 Oregon

A very small percentage of Oregonians access VAD on the basis of CKD.⁸³ CKD satisfies the disease criterion under the *Oregon Act*, as it is incurable and irreversible and can be a terminal condition.⁸⁴ As in Australia, prognosticating about six months until death and potential loss of capacity present challenges for eligibility.

75 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.

76 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’ (Clinical Guidelines No 182, National Institute for Health Care Excellence, July 2014) ch 7 <<https://www.ncbi.nlm.nih.gov/books/NBK328138/>>.

77 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 has received, a kidney transplant.

78 *Victorian Act 2017* (Vic) s 9(1)(d)(ii); *WA Act 2019* (WA) s 16(1)(c)(i).

79 *Victorian Act 2017* (Vic) s 9(1)(d)(iii); *WA Act 2019* (WA) s 16(1)(c)(ii).

80 *Victorian Act 2017* (Vic) s 9(1)(c); *WA Act 2019* (WA) s 16(1)(d).

81 Model Bill (n 2) cl 9(e)(ii).

82 Ibid cl 9(c).

83 ‘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 9) 11, 13.

84 *Oregon Act*, Or Rev Stat §127.800(12) (1994).

5 Canada

A person with CKD will meet the serious and incurable condition requirement on diagnosis.⁸⁵ However, they must also be in an ‘advanced state of irreversible decline’.⁸⁶ Barring a 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.⁸⁷

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 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

Dementia, which refers to a number of neurological conditions where the major symptom is a global decline in brain function,⁸⁸ is the second leading cause of death in Australia.⁸⁹ Alzheimer’s disease (‘Alzheimer’s’) is the most common form of dementia, affecting up to 70% of people with dementia.⁹⁰ 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

85 Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(2)(a).

86 *Ibid* s 241.2(2)(b).

87 *Ibid* s 241.2(3.2).

88 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.

89 Australian Bureau of Statistics, *Causes of Death, Australia, 2018* (Catalogue No 3303.0, 25 September 2019).

90 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.

into three broad stages: mild, moderate and advanced.⁹¹ 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.⁹²

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

It is very unlikely that a person with Alzheimer's will be eligible to access VAD under the *Victorian Act* or *WA Act*. Although Alzheimer's is an incurable disease that is progressive and will cause death,⁹³ it impairs decision-making capacity.⁹⁴ 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),⁹⁵ it is very unlikely they would have capacity to make decisions about VAD.⁹⁶

3 Model Bill

The position is the same under the Model Bill. 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.⁹⁷

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.⁹⁸ Indeed, access is even less likely given the shorter time limit of six months until death.⁹⁹

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- 91 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.
- 92 O Zanetti, SB 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.
- 93 *Victorian Act 2017* (Vic) s 9(1)(d)(ii); *WA Act 2019* (WA) s 16(1)(c)(i).
- 94 *Victorian Act 2017* (Vic) s 9(1)(c); *WA Act 2019* (WA) s 16(1)(d).
- 95 *Victorian Act 2017* (Vic) s 9(4); *WA Act 2019* (WA) s 16(1)(c)(ii).
- 96 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.
- 97 Model Bill (n 2) cl 9(c).
- 98 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/>>.
- 99 *Oregon Act*, Or Rev Stat § 127.800(12) (1994).

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 'advanced state of irreversible decline in capability' before they lose decision-making capacity.¹⁰⁰

There have been a small number of cases in Canada where people with dementia as their sole underlying medical condition accessed VAD.¹⁰¹ 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*,¹⁰² and the assessing physicians acted reasonably and appropriately when considering the issues of capacity and consent.¹⁰³

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 Assessors and Providers.¹⁰⁴ The guideline indicates individuals with dementia will be in an advanced state of irreversible decline in capability just prior to when 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.

100 Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(2)(b).

101 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'.

102 Canadian *Criminal Code*, RSC 1985, c C-46.

103 Letter from JG 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').

104 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>>.

6 Summary

Access to VAD on the basis of Alzheimer's is very unlikely under the *Victorian Act*, *WA Act* and *Oregon Act*. 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, 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.

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.¹⁰⁵ 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.¹⁰⁶ Anorexia affects between 0.3% and 1.5% of Australian women, and between 0.1% and 0.5% of Australian men.¹⁰⁷

While anorexia is not in itself a terminal illness,¹⁰⁸ in some cases, the physical consequences of long-term starvation can become life-threatening. Some describe

105 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) 291.

106 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.

107 *NEDC Report* (n 106) 7, based on international epidemiological data reported in James I Hudson et al, 'The Prevalence and Correlates of Eating Disorders in the National Comorbidity Survey Replication' (2007) 61(3) *Biological Psychiatry* 348.

108 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.

this as ‘end-stage anorexia’¹⁰⁹ or ‘terminal psychiatric disease’.¹¹⁰ Mortality rates vary between 3% and 25%.¹¹¹ In some particularly refractory cases of anorexia, treatment has been assessed as futile, and palliative care¹¹² or VAD¹¹³ has been offered, although both the terminology and the futility of ongoing treatment are disputed.¹¹⁴

It remains unresolved whether the physical sequelae 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.¹¹⁵

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 values¹¹⁶ affecting the ability to choose between treatment options,

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- 109 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; 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.
- 110 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.
- 111 *Ibid*; Gans and Gunn Jr (n 109).
- 112 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 Jr (n 109) at 678, and the cases of ‘Alison’ and ‘Emily’ described in Campbell and Aulisio (n 109) at 628. See also *Re E (Medical Treatment: Anorexia)* [2012] EWCOP 1639; *An NHS Foundation Trust v X* [2014] EWCOP 35 (‘*NHS v X*’).
- 113 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* (Web Page, 1 January 2016) <<https://english.euthanasiecommissie.nl/judgments/d/d-psychiatric-disorders/documents/publications/judgments/2016/2016-01/2016-01>> (‘Regional Euthanasia Review Committees’).
- 114 Cynthia Geppert, ‘Futility in Chronic Anorexia Nervosa: A Concept Whose Time Has Not Yet Come’ (2015) 15(7) *American Journal of Bioethics* 34, 36.
- 115 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) 4 ACTLR 68, 77 [62] (Higgins CJ); *B v Croydon Health Authority* [1995] Fam 133, 138–9 (Hoffman LJ).
- 116 Louis C Charland, ‘Ethical and Conceptual Issues in Eating Disorders’ (2013) 26(6) *Current Opinion in Psychiatry* 562; Jacinta AO Tan et al, ‘Competence to Make Treatment Decisions in Anorexia Nervosa: Thinking Processes and Values’ (2006) 13(4) *Philosophy, Psychiatry, and Psychology* 267.

and disorders of executive function affecting rationality of decisions.¹¹⁷ Starvation also affects cognitive function, including comprehension and reasoning.¹¹⁸ Some believe that each person with anorexia must be individually assessed to determine whether decision-making capacity is present despite these impairments.¹¹⁹ However, others suggest that people with anorexia may *a priori* lack capacity, at least concerning treatment of that condition.¹²⁰ 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.¹²¹

2 Victoria

A person with anorexia will ordinarily not be able to access VAD for this condition. This is because the *Victorian Act* specifically excludes access to VAD based solely on a mental illness.¹²² 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.¹²³

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

117 Geppert (n 114).

118 Tan et al (n 116) 270.

119 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 109); Heather Draper, 'Anorexia Nervosa and Respecting a Refusal of Life-Prolonging Therapy: A Limited Justification' (2000) 14(2) *Bioethics* 120. Gans and Gunn Jr (n 109) articulate a series of specific criteria for determining whether an anorexic person has capacity to choose to die: 693–4.

120 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 116). In *Re E (Medical Treatment: Anorexia)* [2012] EWCOP 1639, Jackson J acknowledged that a person with anorexia may never have capacity to make decisions concerning treatment for that condition: at [49]–[53]. Note though in *NHS v X* [2014] EWCOP 35, 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: at [30], [33]–[34] (Cobb J).

121 Sneiderman and Verhoef (n 113). 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 113). There are also reports of cases where a person with anorexia has been able to access VAD in Canada: see, 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/>>.

122 *Victorian Act 2017* (Vic) s 9(2). The definition of 'mental illness' in section 3 of the *Victorian Act 2017* (Vic) refers to section 4(1) of the *Mental Health Act 2014* (Vic), 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 therefore fall within this definition.

123 For example, in *NHS v X* [2014] EWCOP 35, 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).

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* that a condition may be regarded as causing death if it causes a chain of events that will result in death.¹²⁴ Without an authoritative ruling on those issues, it is not possible to be certain about eligibility under the *Victorian Act* on the basis of anorexia.

In any event, a lack of decision-making capacity is very likely to preclude access. Currently, no English¹²⁵ or Australian cases¹²⁶ have found a person with severe anorexia to have capacity to make decisions refusing treatment for anorexia.¹²⁷ A similar outcome is likely in 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.¹²⁸ People suffering the medical sequelae of prolonged starvation may expect death to occur within six months. By this stage, the condition is likely to 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*. 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.¹²⁹

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, access still remains unlikely given issues of decision-making capacity.

The Model Bill has two relevant differences from the *Victorian Act*. The first is that there is no specific statement precluding access to VAD on the basis of

124 See White et al, 'Comparative and Critical Analysis of Key Eligibility Criteria for VAD' (n 1) Part II(B)(4).

125 *Re E (Medical Treatment: Anorexia)* [2012] EWCOP 1639; *An NHS Trust v L* [2013] EWHC 4313 (Fam); *NHS v X* [2014] EWCOP 35; *Re W (Medical Treatment: Anorexia)* [2016] EWCOP 13; *Cheshire & Wirral Partnership NHS Foundation Trust v Z* [2016] EWCOP 56.

126 *Fletcher v Northern Territory* (2017) 324 FLR 11.

127 However, a person with severe anorexia has been held to have capacity to refuse treatment for comorbid liver disease: *NHS v X* [2014] EWCOP 35.

128 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 et al (eds), *Managing Severe and Enduring Anorexia Nervosa: A Clinician's Guide* (Routledge, 2016) 1.

129 Contrast the result in England in the case of *Re E (Medical Treatment: Anorexia)* [2012] EWCOP 1639.

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 still requires the condition be incurable and will cause death.¹³⁰ 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* 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 depression impairing judgment'¹³¹ 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.¹³² This amounts to a categorical exclusion in contrast with the *Victorian Act*¹³³ and *WA Act*¹³⁴ 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 Act* and *WA Act*, mental illness cannot be considered an 'illness, disease or disability',¹³⁵ 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

130 Model Bill (n 2) cls 9(e)(i)–(ii).

131 *Oregon Act*, Or Rev Stat (1994) § 127.825.

132 Ibid § 127.825.

133 *Victorian Act 2017* (Vic) s 9(2).

134 *WA Act 2019* (WA) s 16(2).

135 Canadian *Criminal Code*, RSC 1985, c C-46, ss 241.2(2)(a), (2.1).

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.¹³⁶

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, which does not specifically prohibit access on the basis of mental illness. Under the Canadian *Criminal Code*,¹³⁷ 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 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.¹³⁸ It reflects the cumulative effects of disease and physiological changes that can occur as people age. It is

136 Ibid s 241.2(2)(b).

137 Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(2).

138 Andrew Clegg et al, ‘Frailty in Elderly People’ (2013) 381(9868) *Lancet* 752, 752.

multidimensional, and clinical manifestations vary widely. Consequently, frailty is generally considered a syndrome rather than a disease.¹³⁹ Prevalence is difficult to ascertain,¹⁴⁰ but estimates suggest that over 415,000 Australians experience frailty.¹⁴¹ The physical indicators of frailty have traditionally included reduced activity, slowing of mobility, weight loss, and exhaustion,¹⁴² but more recently the contribution of psychological, social and environmental factors to frailty have been acknowledged.¹⁴³ Consistently, longitudinal studies have reported that physical frailty also predicts the onset of future cognitive decline and dementia.¹⁴⁴ Frailty can progress through a number of stages¹⁴⁵ and is characterised by an inability to recover to baseline function after a minor stressor, such as an infection.¹⁴⁶

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.¹⁴⁷ 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.¹⁴⁸ 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.¹⁴⁹ Consequently, older frail people find themselves in an ‘uncertain and dwindling process of dying’.¹⁵⁰

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

139 Matteo Cesari et al, ‘Frailty: An Emerging Public Health Priority’ (2016) 17(3) *Journal of the American Medical Directors Association* 188, 190.

140 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.

141 Danielle Taylor et al, ‘Geospatial Modelling of the Prevalence and Changing Distribution of Frailty in Australia – 2011 to 2027’ (2019) 123 *Experimental Gerontology* 57.

142 Linda P Fried et al, ‘Frailty in Older Adults: Evidence for a Phenotype’ (2001) 56(3) *Journal of Gerontology: Medical Sciences* M146.

143 RE Pel-Littel et al, ‘Frailty: Defining and Measuring of a Concept’ (2009) 13(4) *Journal of Nutrition, Health and Aging* 390, 392.

144 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.

145 See, eg, Kenneth Rockwood et al, ‘A Global Clinical Measure of Fitness and Frailty in Elderly People’ (2005) 173(5) *Canadian Medical Association Journal* 489.

146 Clegg et al (n 138).

147 Pel-Littel et al (n 143) 391.

148 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.

149 Ibid.

150 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.

the *Victorian Act*,¹⁵¹ *WA Act*¹⁵² and *Oregon Act*,¹⁵³ and the Model Bill,¹⁵⁴ so access to VAD is not possible on the basis of frailty alone under these frameworks.

3 Canada

Individuals can and have received VAD in Canada on the basis of ‘complex disease/clinical frailty’.¹⁵⁵ 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.¹⁵⁶ 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.¹⁵⁷

4 Summary

Access to VAD for frailty is not possible under the *Victorian Act*, *WA Act*, *Oregon Act* or the Model Bill. 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

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

151 *Victorian Act 2017* (Vic) s 9(1)(d)(ii).

152 *WA Act 2019* (WA) s 16(1)(c)(i).

153 *Oregon Act*, Or Rev Stat § 127.800(12) (1994).

154 Model Bill (n 2) cl 9(e)(ii).

155 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 ‘[t]he category of “other conditions” includes a range of conditions, with frailty commonly cited’: *Canadian First Annual Report* (n 9) 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) 6. 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, 676.

156 Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(2)(a).

157 *Ibid* s 241.2(2)(b).

from the chest down, sparing the arms.¹⁵⁸ SCI can affect sensation, control of the limbs and bowel and bladder function. This can be complete or incomplete.¹⁵⁹ SCI may be caused by a single traumatic incident, such as an accident, injury, stroke, or as a complication of medical care or surgery.¹⁶⁰ 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.¹⁶¹

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,¹⁶² but many do not. Some require artificial nutrition and hydration, but others are able to ingest food and drink orally.¹⁶³ Some are completely paralysed from the neck down, whereas others have partial movement in their arms and hands.¹⁶⁴ Many are wheelchair-bound, but others retain limited mobility.¹⁶⁵

The prevalence of SCI in Australia is less than 0.1% of the population.¹⁶⁶ SCIs are generally persisting conditions¹⁶⁷ which are neither progressive nor fatal, but people with SCI have a higher mortality rate and lower life expectancy.¹⁶⁸ They appear to be more susceptible to diseases such as pneumonia, influenza and heart disease.¹⁶⁹

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- 158 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.
- 159 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.
- 160 For the causes of SCI in Australia, see Amanda Tovell, *Spinal Cord Injury, Australia, 2014–15* (Report, Australian Government, Australian Institute of Health and Welfare, Injury Research and Statistics Series No 113, Catalogue No INJCAT 202, 16 May 2018) vi, 39 ('*SCI, Australia Statistics*').
- 161 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.
- 162 Rita Galeiras Vázquez et al, 'Respiratory Management in the Patient with Spinal Cord Injury' (2013) *BioMed Research International* 168757:1–12.
- 163 Ginette Thibault-Halman et al, 'Acute Management of Nutritional Demands after Spinal Cord Injury' (2011) 28(8) *Journal of Neurotrauma* 1497.
- 164 Christopher S Ahuja et al, 'Traumatic Spinal Cord Injury: Repair and Regeneration' (2017) 80(3 Supp 1) *Neurosurgery* S9.
- 165 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.
- 166 World Health Organization, The International Spinal Cord Society and Jerome Bickenbach (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 PJ O'Connor, 'Prevalence of Spinal Cord Injury in Australia' (2005) 43 *Spinal Cord* 42.
- 167 Tovell, *SCI, Australia Statistics* (n 160) 2, 4.
- 168 Ibid 2.
- 169 *International Perspectives on SCI* (n 166) 24–5; JW Middleton et al, 'Life Expectancy After Spinal Cord Injury: A 50-Year Study' (2012) 50 *Spinal Cord* 803; RJ Soden et al, 'Causes of Death After Spinal Cord Injury' (2000) 38 *Spinal Cord* 604.

2 *Victoria and Western Australia*

Under the *Victorian Act* and *WA Act*, people with SCI will not generally be eligible for VAD, because both statutes specifically state that a person is not eligible for VAD only because of disability.¹⁷⁰

3 *Model Bill*

The Model Bill, unlike the *Victorian Act* and *WA Act*, 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.¹⁷¹

4 *Oregon*

In Oregon, a person with SCI would not qualify for VAD on that basis as the legislation states that no person shall qualify for assistance to die ‘solely because of ... disability’.¹⁷²

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’.¹⁷³ Tetraplegia and paraplegia are serious and incurable disabilities. In the Canadian case of *Truchon v Procureur Général du Canada*, two wheelchair-bound individuals with serious and incurable disabilities were held to be eligible to access VAD.¹⁷⁴ However, both plaintiffs in that case had degenerative conditions,¹⁷⁵ 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 Jocelyn Downie and Jennifer Chandler, consider a decline in capability as a result of an SCI which has since stabilised to satisfy this criterion, whereas others believe the decline must be ongoing.¹⁷⁶

170 *Victorian Act 2017* (Vic) s 9(3); *WA Act 2019* (WA) s 16(2).

171 Model Bill (n 2) cls 9(e)(i)–(ii).

172 *Oregon Act*, Or Rev Stat § 127.805(2) (1994).

173 *Canadian Criminal Code*, RSC 1985, c C-46, s 241.2(2)(b).

174 *Truchon* [2019] QCCS 3792.

175 Jean Truchon had cerebral palsy coupled with degenerative spinal stenosis and myelomalacia, and Nicole Gladu suffered from degenerative post-polio syndrome.

176 White et al, ‘Comparative and Critical Analysis of Key Eligibility Criteria for VAD’ (n 1) 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.

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, 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.¹⁷⁷ This article considers adult-onset Huntington’s, which typically develops between 30 to 50 years of age,¹⁷⁸ however it can manifest at any age from infancy.¹⁷⁹ If one parent has Huntington’s, a child has a 50% chance of developing the condition.¹⁸⁰ It is incurable¹⁸¹ and death typically occurs around 15 to 25 years after the first symptoms, usually from disease complications (such as pneumonia).¹⁸²

Traditionally, five stages of Huntington’s are used in research: early, early intermediate, late intermediate, early advanced and advanced.¹⁸³ 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.¹⁸⁴

177 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.

178 National Institute of Neurological Disorders and Stroke, ‘Huntington’s Disease: Hope Through Research’ (Publication, NIH Publication No 17-NS-19, 31 December 2018) 5 <<https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Hope-Through-Research/Huntingtons-Disease-Hope-Through>>.

179 Francis O Walker, ‘Huntington’s Disease’ (2007) 369(9557) *Lancet* 218, 218.

180 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.

181 Ibid 98.

182 Ibid 97.

183 The Huntington’s Disease Functional Capacity Scale was developed by Ira Shoulson: Ira Shoulson and Stanley Fahn, ‘Huntington Disease: Clinical Care and Evaluation’ (1979) 29 *Neurology* 1, 2; Ira Shoulson, ‘Huntington Disease: Functional Capacities in Patients Treated with Neuroleptic and Antidepressant Drugs’ (1981) 31(10) *Neurology* 1333.

184 ‘How Does Huntington’s Disease Progress?’, *Huntington’s NSW and ACT* (Web Page, 2019) <<https://webarchive.nla.gov.au/awa/20160301160906/http://www.huntingtonsnsw.org.au/information/hd-facts/how-does-huntingtons-disease-progress>>. See Ian Freckelton, ‘Huntington’s Disease and the Law’ (2010) 18(1) *Journal of Law and Medicine* 7.

2 *Victoria and Western Australia*

Huntington's is an incurable disease (required in Victoria only),¹⁸⁵ 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*

There will be a similar outcome under the Model Bill. While the Model Bill does not require a prognostic timeframe, the disease must still be 'advanced'.¹⁸⁶ 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',¹⁸⁷ but the person will likely not retain capacity at the point when the disease is expected to 'produce death within six months'.¹⁸⁸

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'.¹⁸⁹ Particularly if this criterion is assessed by reference to the individual's prior capability rather than an objective standard,¹⁹⁰ 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 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).¹⁹¹

185 *Victorian Act 2017* (Vic) s 9(1)(d)(ii).

186 Model Bill (n 2) s 9(e)(ii).

187 *Oregon Act*, Or Rev Stat § 127.800(12) (1994).

188 *Ibid* § 127.805(1).

189 Canadian *Criminal Code*, RSC 1985, c C-46, ss 241.2(2)(a)–(b).

190 *IRPP Report* (n 16). See also White et al, 'Comparative and Critical Analysis of Key Eligibility Criteria for VAD' (n 1) Part II(F)(2)(b).

191 See *IRPP Report* (n 16).

6 Summary

A person with Huntington's will not be eligible for VAD in Victoria, Western Australia, under the Model Bill 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 framing of the person being in an 'advanced state of irreversible decline of capability',¹⁹² 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 analysis¹⁹³) 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.

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.¹⁹⁴ 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.

192 Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(2)(b).

193 White et al, 'Comparative and Critical Analysis of Key Eligibility Criteria for VAD' (n 1).

194 Although we note that two of the authors have done this in relation to the Model Bill: see (n 2).

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 sequelae, provided capacity retained	No, because a mental illness. Remote possibility for severe cases on basis of physical sequelae, 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 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 the eligibility criteria in the *Victorian Act*,¹⁹⁵ *WA Act*¹⁹⁶ and *Oregon Act*,¹⁹⁷ and the Model Bill.¹⁹⁸ 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*¹⁹⁹ 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’,²⁰⁰ 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’.²⁰¹ 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*,²⁰² 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

195 *Victorian Act 2017* (Vic) s 9.

196 *WA Act 2019* (WA) s 16.

197 *Oregon Act*, Or Rev Stat § 127.805 (1994).

198 Model Bill (n 2) cl 9.

199 Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(1).

200 *Ibid* s 241.2(1)(c).

201 *Ibid* ss (2)(a)–(b).

202 *Ibid* s 241.2(2)(b).

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 illustrated by comparing access to VAD under the *Victorian Act*²⁰³ (a time limit of six and sometimes 12 months until death) with the Model Bill²⁰⁴ (very similar eligibility criteria, but no time limit, requiring only that the condition cause death). For eight of the nine conditions considered in this article, potential eligibility under the Model Bill was the same as in Victoria.²⁰⁵ The sole possible exception was for anorexia, which possibly could be eligible under the Model Bill (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. This is because the Model Bill's requirement for a person's medical condition to be 'advanced' constrains access to similar cases.²⁰⁶

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,²⁰⁷ it is effective. One of the conclusions of this comparative analysis is that the time limits in the *Victorian Act*, *WA Act* and *Oregon Act* restrict access to a later stage in a person's medical condition than under the Model Bill.

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

203 *Victorian Act 2017* (Vic) s 9(1)(d)(iii).

204 Model Bill (n 2) cl 9(e).

205 This same result also applies in relation to the *WA Act 2019* (WA) s 16(1)(c)(ii) and *Oregon Act*, Or Rev Stat § 127.800(12) (1994). The rationale for the specific comparison between the *Victorian Act* and the Model Bill 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.

206 Model Bill (n 2) cl 9(e)(ii).

207 Indeed, the intention of the *Victorian Act* was that VAD would only be available for those people who are 'close to death' and at the 'end of life': *MAP Report* (n 38) 13–14.

fall within the prescribed proximity until death.²⁰⁸ Requiring a specified time limit until death also risks preventing otherwise eligible people from accessing VAD, if the delay until death is approaching means that they are no longer 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 to have 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.²⁰⁹ The progression of some conditions can have a 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.²¹⁰ Nevertheless, community desire remains high for mechanisms to support access to VAD for conditions such as Alzheimer's after a loss of capacity.²¹¹ This has led to some jurisdictions specifically identifying

208 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?').

209 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.

210 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(2–3) *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 Jongasma, Marijke C Kars and Johannes JM 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 YH 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 ss 241.2(3.2), (3.5) of the Canadian *Criminal Code*, RSC 1985, c C-46).

211 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, Ministerial Expert Panel on Voluntary Assisted Dying: A Response from Dementia Australia, *Ministerial Expert Panel on Voluntary Assisted Dying* (May 2019) 7; *Queensland Parliamentary Report* (n 3) 123–5.

this issue as warranting further consideration.²¹² We support this, and 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)²¹³ and mental illness (all frameworks except the Model Bill).²¹⁴ 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 for stable SCI. In relation to anorexia, however, there may be a different outcome. Under the Model Bill, 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, must retain capacity to seek VAD and this is highly unlikely.) Although these criteria are identical in the *Victorian Act*, and very similar in the *WA Act*, 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

212 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, 1st Sess, 42nd Parl, 2016, cl 9.1(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: Department of Justice, ‘Canada’s New Medical Assistance in Dying (MAiD) Law’, *Government of Canada* (Web Page, 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 3) 127 ‘Recommendation 7’. See also the ‘Statement of Reservation’ of Michael Berkman MP, supporting further research into this issue: at 197–8.

213 *Victorian Act 2017* (Vic) s 9(3); *WA Act 2019* (WA) s 16(2); *Oregon Act*, Or Rev Stat § 127.805(2) (1994).

214 *Victorian Act 2017* (Vic) s 9(2); *WA Act 2019* (WA) s 16(2); *Oregon Act*, Or Rev Stat § 127.825 (1994). The exclusion of access to VAD on the basis of mental illness in Canada is proposed in Bill C-7, 2nd Sess, 43rd Parl, 2021, cl 1(2) (as passed by the House of Commons 17 March 2021), amending Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(2.1).

invites the question whether a blanket exclusion from access to VAD based on mental illness is justifiable when the eligibility criteria are otherwise met.²¹⁵

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

The comparative legal analysis in the first article²¹⁶ in this two-part series identified important implications for designing VAD regulation. This Part extends that work and 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 policymakers 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 policymakers' 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 article, eligibility criteria in VAD frameworks are intended to operate holistically.²¹⁷ This was clear on the face of the legislation and from the comparative legal analysis, but became particularly apparent when these

215 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, 2nd Sess, 43rd Parl, 2021, cl 3.1 (as passed by the House of Commons 17 March 2021).

216 White et al, 'Comparative and Critical Analysis of Key Eligibility Criteria for VAD' (n 1).

217 *Ibid* Part IV(C).

criteria were applied to the nine medical conditions. An illustration of this is that differently formulated eligibility 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,²¹⁸ 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.²¹⁹ 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.²²⁰ As a result of this (and other factors), access to VAD in Canada is broader than under the other frameworks.

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.²²¹ 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.²²² In other words, there is a risk

218 *Victorian Act 2017* (Vic), s 9(1)(d)(i); Model Bill (n 2) cl 9(e)(i).

219 *Victorian Act 2017* (Vic), ss 9(1)(d)(iii) and 9(4); *WA Act 2019* (WA) s 16(1)(c)(ii); Model Bill (n 2) cl 9(e).

220 Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(2)(a)–(b).

221 White et al, 'Comparative and Critical Analysis of Key Eligibility Criteria for VAD' (n 1) Part IV(A); Karen Yeung, 'Regulating Assisted Dying' (2012) 23(2) *King's Law Journal* 163.

222 Yeung (n 221) 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 38) 43–6 and evaluated in White et al, 'Does the VAD Act Reflect its Stated Policy Goals?' (n 208). In relation to Western Australia, see Ministerial Expert Panel on Voluntary Assisted Dying, Department of Health (WA), *Final Report* (Report, 27 June 2019). The values underpinning the model Bill are set out in Model Bill (n 2) 6; 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 the *Charter* (n 5).

that individuals whom the policy intent was to permit access to 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.

This is illustrated in Victoria where the Ministerial Advisory Panel, whose recommendations underpinned the Act, 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"'²²³ 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 the 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'.²²⁴ 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.²²⁵ 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 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

223 *MAP Report* (n 38) 81.

224 *Ibid* 82.

225 Yeung (n 221) 168–9.

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.²²⁶ 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.²²⁷ However, this may not occur; 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.²²⁸ Decisions by regulators in particular cases, if made public by the regulator or the clinician investigated, may also contribute to interpretation of statutory provisions.²²⁹ And one of the authors, academic Jocelyn Downie, has

226 Ibid 168–70; Lutz-Christian Wolff, 'Law and Flexibility: Rule of Law Limits of a Rhetorical Silver Bullet' (2011) (11) *Jurisprudence* 549.

227 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.

228 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); College of Physicians and Surgeons of Nova Scotia, 'Professional Standard Regarding Medical Assistance in Dying (MAiD)' (Guideline, 5 May 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>.

229 Two regulatory 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 103); Complaints and Practice Investigations Department, College of Physicians and Surgeons of British

worked with colleagues to clarify key terms in the Canadian *Criminal Code*. This has occurred in a variety of ways including through a policy roundtable process which produced a report with recommended interpretations.²³⁰

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.²³¹ 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 issuing 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 they 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.²³² This establishes a minimum baseline understanding of the legislative framework and provides guidance on how it should be interpreted.²³³

VI CONCLUSION

In this article and its companion article, 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

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/>>.

230 *IRPP Report* (n 16). Downie has also written a series of academic papers analysing and interpreting various aspects of the legislation: Downie and Scallion (n 16); Jocelyn Downie and Justine Dembo, ‘Medical Assistance in Dying and Mental Illness Under the New Canadian Law’ (2016) 9 *Journal of Ethics in Mental Health* 1; Downie and Bowes (n 176); Gus Grant and Jocelyn Downie, ‘Time to Clarify Canada’s Medical Assistance in Dying Law’ (2018) 64(9) *Canadian Family Physician* 641.

231 ‘Judgments’, *Regional Euthanasia Review Committees* (Web Page, 2018) <<https://english.euthanasiecommissie.nl/judgments/>>.

232 *Victorian Act 2017* (Vic) ss 17, 26; *WA Act 2019* (WA) ss 25, 36; Model Bill (n 2) cl 14.

233 Ben P White et al, ‘Development of Voluntary Assisted Dying Training in Victoria, Australia: A Model for Consideration’ (2021) 36(3) *Journal of Palliative Care* 162. Guidance for health practitioners is also provided in other forms: see, eg, Department of Health and Human Services (Vic), ‘Voluntary Assisted Dying: Guidance for Health Practitioners’ (Clinical Guideline, 4 July 2019).

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.²³⁴ 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 policymakers contemplating VAD reform.

VAD reform in further states is being actively considered in Australia.²³⁵ Other countries are also contemplating reform, including the United Kingdom,²³⁶ parts of Europe²³⁷ and other states in the United States.²³⁸ These papers have implications for those reform exercises. In Australia, a particular issue is whether other states should follow the ‘Victorian model’, as Western Australia has substantially done, or take a different path.²³⁹ There can be a tendency to adopt an existing framework, but uncritical acceptance of the Victorian approach must be avoided.²⁴⁰ These comparative analyses raise important questions about the *Victorian Act*’s operation in practice, and provide other models for policymakers 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

234 John C Reitz, ‘How to Do Comparative Law’ (1998) 46(4) *The American Journal of Comparative Law* 617, 624–5.

235 After this article was submitted for publication, voluntary assisted dying laws were passed in three Australian states: the *End-of-Life-Choices (Voluntary Assisted Dying) Act 2021* (Tas); the *Voluntary Assisted Dying Act 2021* (SA) and the *Voluntary Assisted Dying Act 2021* (Qld), respectively. In NSW, the Voluntary Assisted Dying Bill 2021 (NSW) has passed the Legislative Assembly and is set to be debated in the Legislative Council in 2022.

236 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] (Eherton MR, Leveson P and King J).

237 For example, in Portugal, two laws decriminalising VAD have been passed by Parliament but vetoed by the President: ‘Portugal’s President Vetoes Law Legalising Euthanasia’, *Euronews* (online, 30 November 2021) <<https://www.euronews.com/2021/11/30/portugal-s-president-vetoes-law-legalising-euthanasia>>. Spain passed the *Ley Orgánica de regulación de la eutanasia 2021* [Organic Law for the Regulation of Euthanasia] (Spain), which commenced in June 2021. In Germany, in February 2020, the Constitutional Court declared § 217 of the *Strafgesetzbuch* [Criminal Code] (Germany), which criminalised the provision of assisted suicide services, to be 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.

238 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) <<https://www.deathwithdignity.org/in-your-state/>>.

239 Ben White and Lindy Willmott, ‘Future of Assisted Dying Reform in Australia’ (2018) 42(6) *Australian Health Review* 616.

240 The *Victorian Act* 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 208)); 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) 55) 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).

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. It is also important to 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.²⁴¹ 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.²⁴² 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-article series provide an opportunity to inform and support considered law reform and evaluation of that law in Australia and abroad.

241 See *Victorian Act 2017* (Vic) ss 116(1)–(3); *WA Act 2019* (WA) ss 164(1)–(2); Model Bill (n 2) pt 9; Bill C-14, 1st Sess, 42nd Parl, 2016, cls 10(1)–(2); Bill C-7, 2nd Sess, 43rd Parl, 2021, cls 3.1, 5 (as passed by the House of Commons 17 March 2021).

242 Fewer data were available at time of publication from Victoria.