ASSISTED DYING FOR PERSONS WITH DEMENTIA: WHAT ARE THE NEEDED AMENDMENTS OF AUSTRALIAN VOLUNTARY ASSISTED DYING LAWS?

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More than 400,000 Australians are currently living with dementia. Yet those who do not wish to continue living with the illness are likely ineligible for voluntary assisted dying ('VAD') as they do not meet the respective access criteria. While this issue has received recent media attention, it remains under-researched how Australian VAD laws would have to be amended to permit access to persons living with dementia. This article considers this by first analysing the different legislative models granting persons with dementia access to assisted dying as well as access hurdles in the Netherlands and Canada. It subsequently explores how Australian VAD laws would have to be reformed should Australian states elect to allow persons with dementia access to assisted dying.

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I Introduction

More than 400,000 Australians are currently living with dementia,[1] which is defined as a 'syndrome characterized by progressive deficit in cognitive functions, with a major emphasis on memory loss, interfering with social and

[1] Australian Institute of Health and Welfare, 'Summary', *Dementia in Australia* (Web Report, 13 September 2024) <https://www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/summary>, archived at <https://perma.cc/W3SS-YS9W>.

occupational activities'.[2] Estimates suggest that by 2058 this number will have increased to close to 850,000.[3] The illness is the second-most feared clinical condition amongst Australian health service consumers, only preceded by cancer.[4] In 2022, dementia was the second leading cause of death in Australia overall and the leading cause of death for women.[5] It may soon be the leading cause of death.[6]

Voluntary assisted dying ('VAD') in the form of practitioner administration and self-administration of a lethal substance is lawful in all Australian states.[7] Yet there are few options for persons who do not wish to continue to live with dementia in Australia,[8] as they are unlikely to meet eligibility criteria enshrined in Australian VAD laws for reasons analysed in detail in this article. In its 2023 Policy Position Statement, Dementia Australia, the national peak body for

[2] Gustavo C Roman, 'Defining Dementia: Clinical Criteria for the Diagnosis of Vascular Dementia' (2002) 106 (supplementary issue 178) *Acta Neurologica Scandinavica* 6, 6, citing *Diagnostic and Statistical Manual of Mental Disorders* (American Psychiatric Association, 4th rev ed, 2000) 147–8.

[3] Australian Institute of Health and Welfare, 'Summary' (n 1).

[4] Rochelle Watson et al, 'Dementia Is the Second Most Feared Condition among Australian Health Service Consumers: Results of a Cross-Sectional Survey' (2023) 23(1) *BMC Public Health* 876:1–7, 5.

[5] Accounting for 9.3 per cent of all deaths in 2022: Australian Institute of Health and Welfare, 'Deaths Due to Dementia', *Dementia in Australia* (Web Page, 13 September 2024) <https://www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/population-health-impacts-of-dementia/deaths-due-to-dementia>, archived at <https://perma.cc/MPU6-X67Z>.

[6] Australian Bureau of Statistics, *Causes of Death, Australia, 2023* (Catalogue No 3303.0, 10 October 2024) <https://www.abs.gov.au/statistics/health/causes-death/causes-death-australia/2023>, archived at <https://perma.cc/KS53-W5SU>.

[7] *Voluntary Assisted Dying Act 2022* (NSW) s 57(1) ('NSW *VAD Act*'); *Voluntary Assisted Dying Act 2021* (Qld) s 50(1), (2) ('Qld *VAD Act*'); *Voluntary Assisted Dying Act 2021* (SA) ss 63–6 ('SA *VAD Act*'); *End-of-Life Choices (Voluntary Assisted Dying) Act 2021* (Tas) ss 83–4, 86, 89–91 ('Tas *VAD Act*'); *Voluntary Assisted Dying Act 2017* (Vic) ss 45–8 ('Vic *VAD Act*'); *Voluntary Assisted Dying Act 2019* (WA) s 56(1), (2) ('WA *VAD Act*'). While self-administration is the default situation in some Australian states (for example, Vic, WA, SA, Qld) with some narrow exceptions (including inability to self-administer or self-administration determined inappropriate by practitioner) others allow a choice between self- and practitioner administration.

[8] Persons with dementia may make decisions for their future care in an Advance Care Directive ('ACD') including decisions concerning the refusal of care: see generally Adnan Alam et al, 'Advance Care Planning in Dementia: A Qualitative Study of Australian General Practitioners' (2022) 28(1) *Australian Journal of Primary Health* 69, 69; Philippa Trowse, 'Voluntary Stopping of Eating and Drinking in Advance Directives for Adults with Late-Stage Dementia' (2020) 39(2) *Australasian Journal on Ageing* 142, 143–4. However, in Australia, a request to die with assistance in an ACD cannot legally substitute a concurrent request for VAD: at 143–4, 146.

people impacted by dementia in Australia,[9] advocated in the context of VAD for 'choice and a greater engagement with people impacted by dementia to understand how to best empower them to make decisions about their life and death'.[10] The lack of VAD access for persons with dementia in Australia has also attracted recent media coverage drawing attention to this issue.[11] Furthermore, in 2023, during the VAD law reform process in the Australian Capital Territory ('ACT'), the ACT Government 'committed to considering access to VAD for people who have lost decision-making capacity in the future, once the VAD model has been in operation for three years'.[12]

Yet what legislative models are in operation in international jurisdictions permitting access to VAD for persons with dementia, and how Australian VAD laws would have to be modified to accommodate persons with dementia, remains largely under-discussed and under-researched in Australia.[13] This article seeks to contribute to the debate on assisted dying and dementia by identifying how VAD laws in Australian states would have to be reformed to grant access to persons living with dementia by considering the operation of assisted dying

[9] See 'About Dementia Australia', *Dementia Australia* (Web Page) <https://www.dementia.org.au/about-us/dementia-australia>, archived at <https://perma.cc/6AJ3-9B82>.

[10] Dementia Australia, *Dementia and Access to Voluntary Assisted Dying* (Policy Position Statement, April 2023) 5 <https://www.dementia.org.au/sites/default/files/2023-04/Policy-Position-Statements.pdf>, archived at <https://perma.cc/6LK4-4PK9>.

[11] See eg, Melissa Cunningham and Henrietta Cook, 'It Kills Almost 10 Per Cent of Australians: But Dementia Patients Have No Say in How They Die', *The Age* (online, 21 May 2023) <https://www.theage.com.au/national/it-kills-almost-10-per-cent-of-australians-but-dementia-patients-have-no-say-in-how-they-die-20230518-p5d9gm.html>, archived at <https://perma.cc/3JKN-6HW4>; Editorial, 'Euthanasia Law Review Must Consider the Thorny Issue of Dementia', *The Age* (online, 13 June 2023) <https://www.theage.com.au/politics/victoria/euthanasia-law-review-must-consider-the-thorny-issue-of-dementia-20230613-p5dg45.html>, archived at <https://perma.cc/5PQN-KQ2X>; Tim Wong-See, 'Husband Calls for Voluntary Assisted Dying Access for WA Dementia Patients after Wife's Tragic Death', *ABC News* (online, 22 August 2023) <https://www.abc.net.au/news/2023-08-22/calls-for-voluntary-assisted-dying-access-dementia-patients-wa/102755336>, archived at <https://perma.cc/MGQ9-KP47>; David Ames and John Obeid, 'Voluntary Assisted Dying Should Not Be Available to Dementia Patients', *The Sydney Morning Herald* (online, 10 June 2023) <https://www.smh.com.au/national/voluntary-assisted-dying-should-not-be-available-to-dementia-patients-20230607-p5deqo.html>, archived at <https://perma.cc/NP65-KTVE>.

[12] Revised Explanatory Statement, Voluntary Assisted Dying Bill 2023 (ACT) 2, 4, 26.

[13] See generally, Adrienne Matthys, Belinda Cash and Bernadette Moorhead, 'The Representation of Australians Living with Dementia in Voluntary Assisted Dying Research: A Scoping Review' (2024) 43(4) *Australasian Journal on Ageing* 664.

laws in two international jurisdictions, the Netherlands and Canada, which allow access to varying degrees.[14]

The article first outlines the legal obstacles currently preventing persons with dementia from accessing VAD in Australian states. It subsequently comparatively examines how and when persons with dementia are eligible for assisted dying in the Netherlands and Canada and what potential obstacles impede their access. These jurisdictions were selected for comparison as they have assisted dying frameworks which allow persons with dementia access at different stages and do so to varying degrees. In light of the findings of the comparative analysis, the article subsequently ponders what amendments would have to be made to Australian VAD laws should Australian states elect to afford persons living with dementia the choice to access assisted dying. The article does not contemplate whether Australian jurisdictions should grant persons with dementia access to assisted dying. This, including ethical and moral considerations, has been considered by others elsewhere.[15] Instead, the aim of the article is to outline what shape a legislative framework would have to take in Australian jurisdictions to provide access for persons with dementia considering the experiences in international jurisdictions. The article concludes that three distinct eligibility criteria currently enshrined in Australian VAD laws would need to be reformed to allow persons with dementia access to the schemes during the early and late stages of the illness. These criteria are: advanced terminal illness and timeframe-until-death restriction, intolerable suffering and decision-making capacity at all stages of the process.

[14] The article focuses on the legislative situation in Australian states as all State VAD laws are operational. While the ACT passed VAD legislation in June 2024, the law did not commence operation until late 2025: *Voluntary Assisted Dying Act 2024* (ACT) ('ACT *VAD Act*') s 2; 'ACT's Voluntary Assisted Dying Law Passed', *ACT Open Government* (Media Release, 5 June 2024) <https://www.cmtedd.act.gov.au/open_government/inform/act_government_media_releases/barr/2024/acts-voluntary-assisted-dying-law-passed>, archived at <https://perma.cc/R3P8-2FCW>.

[15] See eg, Ben White et al, 'People with Dementia Aren't Currently Eligible for Voluntary Assisted Dying: Should They Be?', *The Conversation* (online, 21 May 2024) <https://theconversation.com/people-with-dementia-arent-currently-eligible-for-voluntary-assisted-dying-should-they-be-224075>, archived at <https://perma.cc/RC8R-64NF>; Paul A Komesaroff et al, 'Should Voluntary Assisted Dying in Victoria Be Extended To Encompass People with Dementia?' (2024) 220(9) *Medical Journal of Australia* 452, 452; William Allen, 'Medical Ethics Issues in Dementia and End of Life' (2020) 22(6) *Current Psychiatry Reports* 31:1–7, 4, 6; Raphael Cohen-Almagor, 'First Do No Harm: Euthanasia of Patients with Dementia in Belgium' (2016) 41(1) *Journal of Medicine and Philosophy* 74, 77; 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, 86–8; Stavroula Tsinorema, 'The Principle of Autonomy and the Ethics of Advance Directives' (2015) 30(1) *Synthesis Philosophica* 73, 74, 76, 80–1, 84–6.

The below considers access to VAD for persons living with dementia in Australia by first providing a background to dementia as a medical condition before identifying legal obstacles to VAD access during different stages of the illness.

II Access for Persons Living with Dementia to VAD in Australian States

A *Dementia*

The term dementia is used as 'an umbrella term for several diseases that are mostly progressive, affecting memory, other cognitive abilities and behaviour, and that interfere significantly with a person's ability to maintain the activities of daily living'.[16] Over time, the diseases underlying dementia 'destroy nerve cells and damage the brain, typically leading to deterioration in cognitive function (ie the ability to process thought) beyond what might be expected from the usual consequences of biological ageing'.[17] Dementia incidences increase with age, making it a more common phenomenon in aging populations.[18] Dementia is ultimately fatal.[19]

The most common form of dementia is Alzheimer's disease, likely amounting to between 60–70 per cent of all cases.[20] The average life expectancy for persons with Alzheimer's is four to eight years after their diagnosis.[21]

During the course of dementia, apart from cognitive decline, a group of clinical phenomena are observable: namely, 'disturbed emotions, mood, perception, thought, motor activity, and altered personality traits'.[22] This also

[16] World Health Organization, *Global Action Plan on the Public Health Response to Dementia 2017–2025* (Brochure, 7 December 2017) 2 <https://iris.who.int/bitstream/handle/10665/259615/9789241513487-eng.pdf?sequence=1>, archived at <https://perma.cc/ZW5F-PLNN>.

[17] 'Dementia', *World Health Organization* (Web Page, 31 March 2025) <https://www.who.int/news-room/fact-sheets/detail/dementia>, archived at <https://perma.cc/9TRG-HE5Y>.

[18] EL Cunningham et al, 'Dementia' (2015) 84(2) *Ulster Medical Journal* 79, 79.

[19] Mette L Rurup et al, 'Attitudes of Physicians, Nurses and Relatives towards End-of-Life Decisions Concerning Nursing Home Patients with Dementia' (2006) 61(3) *Patient Education and Counseling* 372, 372.

[20] World Health Organization, *Global Action Plan on the Public Health Response to Dementia 2017–2025* (n 16) 2. Other major forms of dementia are dementia with Lewy bodies, vascular dementia, as well as a group of diseases which 'contribute to frontotemporal dementia': at 2.

[21] 'Stages of Alzheimer's', *Alzheimer's Association* (Web Page) <https://www.alz.org/alzheimers-dementia/stages>, archived at <https://perma.cc/8PAV-53PL>.

[22] J Cerejeira, L Lagarto and EB Mukaetova-Ladinska, 'Behavioral and Psychological Symptoms of Dementia' (2012) 3 *Frontiers in Neurology* 73:1–21, 1.

includes symptoms such as 'agitation, depression, apathy, repetitive questioning, psychosis, aggression, sleep problems, wandering, and a variety of socially inappropriate behaviours'.[23]

Dementia is seen to progress in three different stages: mild, moderate, and severe.[24] Studies have shown that how prominent symptoms are depends not only on the illness itself but also on the stage of the illness.[25] It has been found that many persons in the early stages of Alzheimer's, for example, experience depression and anxiety which can worsen over time.[26] In addition, persons with dementia commonly and persistently experience agitation including 'excessive psychomotor activity such as pacing, trailing, restlessness, dressing and undressing, and emotional distress' which may increase as the disease becomes more severe.[27] Hallucinations, aggression and delusion have been described as 'more episodic and more common in moderate to severe stages of the disease'.[28] All types of dementia can impair the capacity to make decisions.[29]

The legal hurdles faced by persons living with dementia in Australian states when wishing to access VAD are analysed below.

B *Australian VAD Access Criteria*

Access to VAD in Australian states requires a person to be diagnosed with an illness, medical condition or disease.[30] In addition, the condition, illness or disease must be advanced, progressive and expected to cause death[31] within a particular timeframe. The timeframe until expected death in the majority of States

[23] Helen C Kales, Laura N Gitlin and Constantine G Lyketsos, 'Assessment and Management of Behavioral and Psychological Symptoms of Dementia' (2015) 350 *British Medical Journal* 369:1–16, 1, citing Constantine G Lyketsos et al, 'Neuropsychiatric Symptoms in Alzheimer's Disease' (2011) 7(5) *Alzheimer's & Dementia* 532, 533.

[24] See, eg, Ee Heok Kua et al, 'The Natural History of Dementia' (2014) 14(3) *Psychogeriatrics* 196, 197–8.

[25] Ibid 198–9.

[26] Kales, Gitlin and Lyketsos (n 23) 2.

[27] Ibid (citations omitted).

[28] Ibid, citing Lyketsos et al (n 23) 532.

[29] R Ryan Darby and Bradford C Dickerson, 'Dementia, Decision-Making, and Capacity' (2017) 25(6) *Harvard Review of Psychiatry* 270, 270, citing Ezequiel Gleichgerrcht et al, 'Decision-Making Cognition in Neurodegenerative Diseases' (2010) 6 (November) *Nature Reviews Neurology* 611, 611.

[30] NSW *VAD Act* (n 7) s 16(1)(d); Qld *VAD Act* (n 7) s 10(1)(a); SA *VAD Act* (n 7) s 26(1)(d); Tas *VAD Act* (n 7) ss 6(1), 10(1)(e); Vic *VAD Act* (n 7) s 9(1)(d); WA *VAD Act* (n 7) s 16(1)(c).

[31] NSW *VAD Act* (n 7) s 16(1)(d)(i); Qld *VAD Act* (n 7) s 10(1)(a)(i); SA *VAD Act* (n 7) ss 26(1)(d)(ii); Tas *VAD Act* (n 7) s 6(1)(a)–(b); Vic *VAD Act* (n 7) s 9(1)(d)(ii); WA *VAD Act* (n 7) s 16(1)(c)(i). The Tasmanian legislation does not require the illness to be progressive.

is generally no more than six months.[32] Yet if a person suffers from a neurodegenerative disease in Victoria, Western Australia ('WA'), Tasmania, South Australia ('SA') and New South Wales ('NSW'), it is no more than 12 months until expected death.[33] Irrespective of the nature of the disease, illness or condition, in Queensland death must be expected to occur within 12 months.[34] The illness or medical condition must also cause a person intolerable suffering.[35] When accessing VAD, a person must have decision-making capacity regarding VAD during the entire process, including during the required three requests for VAD and during the administration of the substance.[36] They must act voluntarily and their request must be enduring.[37]

C *Access during the Early Stages of Dementia*

Dementia is an illness which is progressive and expected to cause death, thus satisfying the access requirement enshrined in the VAD laws of all Australian States.[38] As dementia is considered a neurodegenerative disease,[39] a person

[32] NSW *VAD Act* (n 7) s 16(1)(d)(ii)(B); SA *VAD Act* (n 7) s 26(1)(d)(iii); Tas *VAD Act* (n 7) s 6(1)(c)(i); Vic *VAD Act* (n 7) s 9(1)(d)(iii); WA *VAD Act* (n 7) s 16(1)(c)(ii). The exception is Queensland where it is 12 months: Qld *VAD Act* (n 7) s 10(1)(a)(ii). The ACT VAD legislation does not contain a specific timeframe. Rather, it requires a person to be 'approaching the end of their life': ACT *VAD Act* (n 14) ss 11(3)(c), (6).

[33] NSW *VAD Act* (n 7) s 16(1)(d)(ii)(A); SA *VAD Act* (n 7s) s 26(4); Tas *VAD Act* (n 7) s 6(1)(c)(ii); Vic *VAD Act* (n 7) s 9(4); WA *VAD Act* (n 7) s 16(1)(c)(ii).

[34] Qld *VAD Act* (n 7) s 10(1)(a)(ii). On whether timeframe-until-death restrictions in VAD laws comply with human rights in the Australian context: see generally Kerstin Braun, 'When Ill Is Not Ill Enough: Timeframe until Expected Death Restrictions in Australian Voluntary Assisted Dying Laws and Human Rights Compatibility' (2022) 28(1) *Australian Journal of Human Rights* 21, 39.

[35] NSW *VAD Act* (n 7) s 16(1)(d)(iii); Qld *VAD Act* (n 7) s 10(1)(a)(iii); SA *VAD Act* (n 7) s 26(1)(d)(iv); Tas *VAD Act* (n 7) s 10(1)(e); Vic *VAD Act* (n 7) s 9(1)(d)(iv); WA *VAD Act* (n 7) s 16(1)(c)(iii). In Queensland, the illness must cause suffering that the person considers intolerable while in Tasmania the person must suffer intolerably. In New South Wales, South Australia, Victoria and Western Australia the illness must cause suffering that cannot be relieved in a way the person finds tolerable.

[36] NSW *VAD Act* (n 7) s 16(1)(e); Qld *VAD Act* (n 7) s 10(1)(b); SA *VAD Act* (n 7) s 26(1)(c); Tas *VAD Act* (n 7) s 10(1)(c); Vic *VAD Act* (n 7) s 9(1)(c); WA *VAD Act* (n 7) s 16(1)(d).

[37] NSW *VAD Act* (n 7) ss 16(1)(f)–(h); Qld *VAD Act* (n 7) s 10(1)(c); SA *VAD Act* (n 7) ss 26(1)(e), 38(1)(d); Tas *VAD Act* (n 7) s 10(1)(d); Vic *VAD Act* (n 7) ss 20(1)(c)-(d); WA *VAD Act* (n 7) ss 16(1)(e)–(f). The Tasmanian and Queensland *VAD Acts* do not use the specific term 'enduring'.

[38] See above Part II A . See above n 31.

[39] Carmelle Peisah, Linda Sheahan and Ben P White, 'Biggest Decision of Them All: Death and Assisted Dying' (2019) 49(6) *Internal Medicine Journal* 792, 793.

living with dementia wishing to access VAD must be expected to die within 12 months in all Australian states.

Given the multi-year course of the condition, persons in the early stages of dementia are unlikely to be expected to die within 12 months. In addition, the NSW *VAD Act* explicitly excludes persons from accessing VAD solely because they have dementia.[40]

Consequently, persons in the early stages of dementia are likely ineligible for assisted dying in all Australian states. Whether persons in the later stages of dementia can access VAD is discussed below.

D *Access during the Later Stages of Dementia*

A person seeking access to VAD in Australian states must have decision-making capacity in relation to VAD, they must act voluntarily, and their VAD request must be enduring.

Once a person living with dementia is no more than 12 months away from expected death, they meet the timeframe-until-death requirement. However, to be eligible, at the same time as being expected to die within 12 months, a person must have decision-making capacity regarding VAD during all stages of the VAD process. Soumya Hegde and Ratnavalli Ellajosyula explain that a person living with dementia generally cannot be assumed incapable of decision-making.[41] They note that persons 'with mild to moderate dementia can evaluate, interpret, and derive meaning in their lives'.[42] However, during the later stages of dementia it is likely that a person will have already lost decision-making capacity.[43] Thus persons with dementia expected to die within the required timeframe are likely unable to lawfully request assistance in dying due to lack of decision-making capacity.

VAD instructions requesting that medical practitioners administer VAD substances contained in an advance care directive ('ACD') for the case in which a person becomes non-competent, known in some international jurisdictions as an 'advance euthanasia directive', are currently not lawful in Australia.[44]

[40] NSW *VAD Act* (n 7) s 16(2)(b). This is a unique feature of the NSW Act.

[41] Soumya Hegde and Ratnavalli Ellajosyula, 'Capacity Issues and Decision-Making in Dementia' (2016) 19 (Supplementary Issue 1) *Annals of Indian Academy of Neurology* S34, S35.

[42] Ibid.

[43] Katherine Waller et al, 'Voluntary Assisted Dying in Australia: A Comparative and Critical Analysis of State Laws' (2023) 46(4) *University of New South Wales Law Journal* 1421, 1434.

[44] Some Australian States, for example South Australia, explicitly prohibit that an ACD can constitute a request for VAD: *Advanced Care Directives Act 2013* (SA) s 12(1a). See also *Medical Treatment Planning and Decisions Act 2016* (Vic) s 8A; *Powers of Attorney Act 1998* (Qld) ss 35, 159.

Consequently, once a person living with dementia loses capacity, they are no longer able to access assisted dying.[45]

Due to the timeframe-until-death restrictions and the requirement to have decision-making capacity in relation to VAD at all stages of the VAD process, persons living with dementia are largely deprived of choice to participate in VAD in Australia.

In contrast, the Netherlands and Canada have created frameworks permitting dementia patients access to VAD under different circumstances. The legal frameworks in these jurisdictions as well as potential access barriers are analysed next.

E *The Netherlands*

In the Netherlands, assisted dying legislation was introduced in 2001 in the form of the *Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001* (the Netherlands) ('*Termination of Life Act*') and commenced operation in 2002.[46] To access assisted dying in the Netherlands, a person's physical or psychological suffering originating from a medical disease[47] must be 'lasting and unbearable' and there must be no other reasonable alternatives for the person.[48] The request to access assisted dying must be 'voluntary and well-considered'.[49] These access restrictions are known as due care requirements and physicians must comply with these requirements in order to avoid criminal liability for a homicide offence under the *Dutch Criminal Code*.[50]

[45] NSW *VAD Act* (n 7) s 16(1)(e); Qld *VAD Act* (n 7) s 10(1)(b); SA *VAD Act 2021* (n 7) s 26(1)(c); Tas *VAD Act* (n 7) s 10(1)(c); Vic *VAD Act* (n 7) s 9(1)(c); WA *VAD Act* (n 7) s 16(1)(d).

[46] *Wet Toetsing Levensbeëindiging op Verzoek en Hulp bij Zelfdoding* [Termination of Life on Request and Assisted Suicide (Review Procedures) Act] (The Netherlands) 1 April 2002 <https://wetten.overheid.nl/BWBR0012410/2021-10-01>, archived at <https://perma.cc/2FTJ-KV96> ('*Termination of Life Act*'); Kumar Amarasekara and Mirko Bagaric, 'The Legalisation of Euthanasia in the Netherlands: Lessons To Be Learnt' (2001) 27(2) *Monash University Law Review* 179, 179. An unofficial English translation of the legislation is available at 'Dutch Law on Termination of Life on Request and Assisted Suicide (Complete Text)', *World Federation Right to Die Societies* (Web Page) <https://wfrtds.org/dutch-law-on-termination-of-life-on-request-and-assisted-suicide-complete-text/>, archived at <https://perma.cc/2533-FGBV>.

[47] See generally Vera E van den Berg et al, 'Requests for Euthanasia or Assisted Suicide of People without (Severe) Illness' (2022) 126(8) *Health Policy* 824, 824.

[48] *Termination of Life Act* (n 46) art 2(1)(b), (d).

[49] Ibid art 2(1)(a).

[50] Ibid art 2(1); *Wetboek van Strafrecht* [Criminal Code] (The Netherlands) art 293(2) <https://wetten.overheid.nl/BWBR0001854/2025-07-01>, archived at <https://perma.cc/

The below considers under what circumstances and at what stages persons living with dementia can access assisted dying in the Netherlands.

1 *Access during the Early Stages of Dementia*

Diagnosed dementia is a medical condition required for access to assisted dying under the *Termination of Life Act*. In addition, the request for assistance in dying must be 'voluntary and well-considered'.[51] Persons with dementia in the early stages, especially, may still have capacity to make an autonomous and voluntary request.[52] After reviewing 32 studies on decision-making capacity concerning persons with dementia, Radboud M Marijnissen and colleagues found that 'the abilities to express a choice and to provide some reasoning for that choice are often preserved in this population, even in those with severe-stage Alzheimer's.'[53]

Moreover, to access assisted dying in the Netherlands, persons living with dementia must suffer unbearably and without having reasonable alternatives. There is a question as to when this arises in the context of dementia. The Dutch Regional Euthanasia Review Committees ('RTEs')[54] published a Euthanasia Code designed to provide medical practitioners involved in assisted dying 'insight into the way in which the RTEs interpret the statutory due care criteria'.[55] The *2022 Euthanasia Code* sets out that in the case of dementia, in the early stages 'a patient's suffering is often partly determined by their fear of further

AD79-F968> ('*Dutch Criminal Code*'). For an unofficial English translation of the legislation, see: *Wetboek van Strafrecht* (The Netherlands) [tr 'Criminal Code', *Antislavery in Domestic Legislation* (Web Document, 1 October 2012)] <https://antislaverylaw.ac.uk/wp-content/uploads/2019/08/Netherlands-Criminal-Code.pdf>, archived at <https://perma.cc/F6SS-N39D>.

51 *Termination of Life Act* (n 46) art 2(1)(a).

52 See Inez D de Beaufort and Suzanne van de Vathorst, 'Dementia and Assisted Suicide and Euthanasia' (2016) 263(7) *Journal of Neurology* 1463, 1464.

53 The review focused on Alzheimer's disease: Radboud M Marijnissen, Kenneth Chambaere and Richard C Oude Voshaar, 'Euthanasia in Dementia: A Narrative Review of Legislation and Practices in the Netherlands and Belgium' (2022) 13 *Frontiers in Psychiatry* 857131:1–14, 5.

54 In the Netherlands, there are five regional euthanasia review committees: 'The Committees', *Regional Euthanasia Review Committees* (Web Page) <https://english.euthanasiecommissie.nl/the-committees>, archived at <https://perma.cc/HM67-A95L>. The committees are tasked with assessing whether a medical practitioner who has assisted someone in dying has done so in accordance with the due care criteria enshrined in the *Termination of Life Act* (n 46).

55 Regional Euthanasia Review Committees, *Euthanasia Code 2022: Review Procedures in Practice* (Code, July 2022) 5 <https://english.euthanasiecommissie.nl/site/binaries/site-content/collections/documents/euthanasia-code/euthanasia-code-2022/euthanasia-code-2022/euthanasia-code-2022/RTE_EuthaCode2022_English.pdf>, archived at <https://perma.cc/RH8E-CZ2M> ('*2022 Euthanasia Code*').

decline and the negative impact on their autonomy and dignity'.[56] The RTE noted that the 'key factor' in determining unbearable suffering 'is the patient's perception of the progressive loss of personality, functions and skills, and the realisation that this process is unstoppable. This prospect can cause profound suffering in the present moment.'[57] Thus, the *2022 Euthanasia Code* suggests that in the Netherlands, the patient's perception and fear of future suffering can be considered when assessing a patient's current unbearable suffering in the context of an assisted dying request.

Consequently, in the Netherlands, some persons living with dementia in the early stages can meet the access criteria for assisted dying. A request for assisted dying while a person is still competent is known as a concurrent or contemporaneous request.[58] In this context, scholars have pointed out that people living with dementia in the early stages frequently will not want to die while they still have capacity and a relatively good quality of life.[59] Yet they may fear that waiting too long means losing capacity to make the decision to die with assistance.[60] In the Netherlands, a person living with dementia, however, may continue to be eligible for assisted dying once they have lost capacity.

2 *Access during the Later Stages of Dementia*

Once a person becomes non-competent, they may be able to access assisted dying in the Netherlands if they have previously drawn up an advance euthanasia directive ('AED') when they were still competent, and meet all other due care access criteria.[61] In this context, the AED can replace an oral access request for assisted dying.[62] This type of request is referred to as an advance request.[63] An AED must include the future circumstances under which the person wishes

[56] Ibid 48.

[57] Ibid.

[58] See 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, 467, 469. See also Radboud Marijnissen, Robert Schoevers and Richard Oude Voshaar, 'Commentary Letter to the Editor on the Study of Mangino et al: Euthanasia and Assisted Suicide of Persons with Dementia' (2020) 28(11) *American Journal of Geriatric Psychiatry* 1229, 1229.

[59] Marijnissen, Chambaere and Voshaar (n 53) 5.

[60] Ibid 5–6, citing Chris Gastmans, 'Dignity-Enhancing Care for Persons with Dementia and Its Application to Advance Euthanasia Directives' in Yvonne Denier, Chris Gastmans and Antoon Vandevelde (eds), *Justice, Luck & Responsibility in Health Care* (Springer, 2013) 145, 152, 157.

[61] *Termination of Life Act* (n 46) art 2(2). See also Marijnissen, Chambaere and Voshaar (n 53) 3.

[62] *2022 Euthanasia Code* (n 55) 38; Caroline van den Ende and Eva Constance Alida Asscher, 'No (True) Right to Die: Barriers in Access to Physician-Assisted Death in Case of Psychiatric Disease, Advanced Dementia or Multiple Geriatric Syndromes in the Netherlands' (2024) 27(2) *Medicine, Health Care and Philosophy* 181, 184.

[63] Mangino et al (n 58) 467.

to access assisted dying once the person becomes non-competent.[64] While there is no specific required format for the AED, patients are advised to specify the circumstances under which they wish to receive assisted dying as much as possible.[65]

When acting upon an AED, the medical practitioner must 'assess whether any contraindications preclude the performance of euthanasia'.[66] In addition, according to the *2022 Euthanasia Code*, the medical practitioner

> must be satisfied that the patient is experiencing unbearable suffering. There may be current unbearable suffering caused by physical illness or injuries, but there may also be current unbearable suffering if the patient is in the situation they described in their advance directive as (expected) unbearable suffering and it can be deduced from the patient's consistent behaviour that they are suffering unbearably. However, the mere circumstance that the patient is in the situation described in the advance directive is not a sufficient basis to conclude that the patient is indeed currently suffering unbearably.[67]

If suffering is not apparent at the time, assisted dying cannot be performed despite the existence of an AED.[68]

The RTE advises medical practitioners that where assisted dying is to be performed during the late stages of dementia, the performing medical practitioner should generally consult two independent medical practitioners prior to assisting the person in dying to ensure the person meets all access criteria.[69] One of these should be a generalist medical practitioner who assesses whether the general access criteria enshrined in the *Termination of Life Act* have been met.[70] The other should be a medical practitioner specialising in dementia, for example, a geriatrician or elderly care specialist, who assesses whether the person wishing to die with assistance is competent.[71] If the person is no longer competent, an AED must be in place in order for the person to be provided with assisted dying. In addition, the specialist should assess whether the person

64 *2022 Euthanasia Code* (n 55) 38.

65 Ibid.

66 Ibid 40.

67 Ibid 41 (citations omitted).

68 Marijnissen, Chambaere and Voshaar (n 53) 7, citing 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(2) *Journal of Medical Ethics* 71, 74.

69 *2022 Euthanasia Code* (n 55) 42.

70 Ibid 27–8, 42.

71 Ibid 42.

living with dementia is 'suffering unbearably with no prospect of improvement, and possible reasonable alternatives'.[72]

In the Netherlands, there is no requirement for the AED to be drawn up with the assistance of a health practitioner.[73] Moreover, it does not have to be witnessed or be registered by a notary.[74] A third party may alert a physician to the existence of the directive[75] and assisted dying based on an AED can be performed by a medical practitioner even if they did not know the person prior to capacity loss. Yet no medical practitioner is under a legal obligation to provide assisted dying based on an AED.[76]

The above shows that some persons living with dementia in the Netherlands can meet the access criteria for assisted dying even after capacity loss. How often persons with dementia in the early and late stages of the illness have received assistance in dying in the 2023 calendar year in the Netherlands is considered below.

3 *Access in Practice*

According to the 2023 RTE's annual report, in the 2023 calendar year the RTEs received 9,068 notifications of assisted dying.[77] A total of 328 cases of assisted dying (around 3.62 per cent) concerned persons with dementia who had decision-making capacity.[78] The report noted that '[t]hese patients still had insight into their condition and its symptoms, such as spatial and temporal disorientation, and personality changes'.[79] Only eight cases of assisted dying (0.088 per cent) concerned non-competent persons in advanced or very advanced stages of dementia.[80] In these eight cases, the persons were no longer able to communicate, and an existing AED was relied upon as the request for assisted dying.[81] Therefore, persons living with dementia constituted just over 3 per cent

[72] Ibid 42.

[73] Ibid 38.

[74] While noting that giving the directive to the practitioner to keep on file is advisable: ibid.

[75] Ibid 18.

[76] Van den Ende and Asscher (n 62) 182.

[77] Regional Euthanasia Review Committees, *Annual Report 2023* (Report, April 2024) 12 <https://english.euthanasiecommissie.nl/site/binaries/site-content/collections/documents/annual-reports/2002/annual-reports/annual-reports/RTE+-Annual-report-2023.pdf>, archived at <https://perma.cc/4VUC-6CKF>.

[78] Ibid 13.

[79] Ibid.

[80] Ibid.

[81] Ibid.

of the total number of persons obtaining assistance in dying in the Netherlands in 2023.[82]

The RTEs found that in five cases of assisted dying (0.055 per cent), the medical practitioner was non-compliant with the relevant due care criteria set out in the *Termination of Life Act* when performing assisted dying.[83] None of these cases concerned issues relating to dementia.[84]

4 *Analysis: Access to Assisted Dying for Persons in the Netherlands*

The above shows that according to Dutch law, persons with dementia who meet all other requirements are permitted to access assisted dying during the early stages of the illness by making a concurrent request. During the later stages of the illness, once they have lost capacity, assisted dying may be provided to persons with dementia based on an AED. The number of assisted dying requests from non-competent persons with dementia is increasing in the Netherlands.[85] Yet statistics make clear that despite the law on the books, persons living with dementia make up a very small percentage of persons obtaining assistance in dying in the Netherlands, especially when assisted dying is based on an AED.

While the law may permit persons with dementia to die with assistance even after they lose capacity this does not mean that medical practitioners are willing to perform assisted dying in these cases for several reasons. Moral and ethical concerns may cause unwillingness in Dutch practitioners to provide assisted dying to non-competent persons with dementia.[86] For example, a qualitative interview study by Jaap Schuurmans and colleagues published in 2019 found that some Dutch practitioners had 'strong moral objections' to providing assisted dying in cases where they were no longer able to 'communicate effectively with their patient'.[87]

[82] Ibid 14.

[83] Ibid 54.

[84] Ibid 54–5, 57–60, 62–3, 65.

[85] Djura O Coers et al, 'Navigating Dilemmas on Advance Euthanasia Directives of Patients with Advanced Dementia' (2024) 25(12) *Journal of the American Medical Directors Association* 105300:1–10, 2, 7.

[86] Van den Ende and Asscher (n 62) 182; Marijnissen, Chambaere and Voshaar (n 53) 7; Cees Hertogh, 'Making Euthanasia Legal in the Netherlands: Implications for the Doctor-Patient Relationship' in Julian C Hughes and Ilora G Finlay (eds), *The Reality of Assisted Dying: Understanding the Issues* (Open University Press, 2024) 38, 40.

[87] Jaap Schuurmans et al, 'Euthanasia Requests in Dementia Cases: What Are Experiences and Needs of Dutch Physicians?' (2019) 20(1) *BMC Medical Ethics* 66:1–9, 3. See also Djura O Coers et al, 'Dealing with Requests for Euthanasia in Incompetent Patients with Dementia: Qualitative Research Revealing Underexposed Aspects of the Societal Debate' (2023) 52(1) *Age and Ageing* 1, 4.

Moreover, several recent studies in the Netherlands identified that the following factors can prevent practitioners from participating: complexities surrounding assessing patients who are no longer competent especially in the context of evaluating the due care criteria;[88] the difficulties associated with working with AEDs;[89] pressures from patients and their families;[90] and the additional requirements when carrying out assisted dying based on an AED.[91] For example, Dutch medical practitioners have pointed out that they find it challenging to assess whether a person with advanced dementia is suffering unbearably in cases where the person is no longer able to verbally communicate.[92] For this reason, many Dutch practitioners noted that they would not perform assisted dying where a person is not verbally able to confirm that they are acting voluntarily and suffering unbearably.[93] Unwillingness to participate in assisted dying based on AED may be even greater among Dutch medical practitioners after the recent so-called 'coffee euthanasia' case, where a physician was subject to a homicide prosecution after providing assisted dying to a non-competent person with dementia based on an AED.[94] In that case, the practitioner did not seek the patient's confirmation on the day and placed a sedative in the patient's coffee prior to administering the substance.[95] Though it ultimately resulted in an acquittal, the case highlighted that a physician's potential misinterpretation of the due care criteria in a particular case can result in a criminal

[88] See Coers et al, 'Navigating Dilemmas on Advance Euthanasia Directives of Patients with Advanced Dementia' (n 85) 2.

[89] Aida Dehkhoda, Richard G Owens and Phillipa J Malpas, 'Conceptual Framework for Assisted Dying for Individuals with Dementia: Views of Experts Not Opposed in Principle' (2021) 20(3) *Dementia* 1058, 1060.

[90] Jaap Schuurmans et al, 'Dutch GPs' Experience of Burden by Euthanasia Requests from People with Dementia: A Quantitative Survey' (2021) 5(1) *BJGP Open* 1, 7. See also Marike E de Boer et al, 'Pressure in Dealing with Requests for Euthanasia or Assisted Suicide: Experiences of General Practitioners' (2019) 45(7) *Journal of Medical Ethics* 425, 426.

[91] Van den Ende and Asscher (n 62) 182.

[92] Pauline SC Kouwenhoven et al, 'Opinions About Euthanasia and Advanced Dementia: A Qualitative Study among Dutch Physicians and Members of the General Public' (2015) 16(1) *BMC Medical Ethics* 7:1–6, 3; Jaap Schuurmans et al, 'Euthanasia in Advanced Dementia: The View of the General Practitioners in the Netherlands on a Vignette Case along the Juridical and Ethical Dispute' (2021) 22(1) *BMC Family Practice* 232:1–7, 4. See also Coers et al (n 85) 4.

[93] Kouwenhoven et al (n 92) 4–5. See also Djura Coers et al, 'Navigating Dilemmas on Advance Euthanasia Directives of Patients with Advanced Dementia' (n 85), noting an increase in doctors who believe unbearable suffering can be assessed in these cases from previously reported studies: at 5–6.

[94] Hoge Raad der Nederlanden [Supreme Court of the Netherlands], 19/04910, ECLI:NL:HR:2020:712, 21 April 2020.

[95] Asscher and van de Vathorst (n 68) 72.

prosecution.[96] Given the complexities of cases in which persons with dementia seek access to assisted dying, Dutch medical practitioners have expressed the need for more support and training to deal with these challenging requests, in circumstances where they are not currently receiving such support.[97]

The reluctance of Dutch practitioners to provide assisted dying to persons with dementia, especially when this is based on an AED, has led some scholars to surmise that 'the limited availability of doctors who are willing to assess or to perform [assisted dying] in these complex cases may result in de facto no access for these cases or extremely long waiting times'.[98] Assisted dying for persons with dementia is also possible according to Canadian law under certain circumstances.

F *Canada*

1 *Access under MAID*

Canada passed medical assistance in dying ('MAID') legislation in 2016.[99] In Canada, a person must have a grievous and irremediable medical condition to access assisted dying.[100] This is the case where a person has an illness, disease or disability which is serious and incurable,[101] is 'in an advanced state of irreversible decline in capability'[102] and the condition or state of decline causes them to endure 'physical or psychological suffering' which is 'intolerable to them and that cannot be relieved under conditions that they consider

[96] For detailed analyses of the case: see generally Henri Wijsbek and Thomas Nys, 'On the Authority of Advance Euthanasia Directives for People with Severe Dementia: Reflections on a Dutch Case' (2022) 52(5) *Hastings Center Report* 24, 24, 26; Martin Buijsen, 'Euthanasia in the Netherlands: History, Developments and Challenges' (2022) 17 *Revista Derecho y Religión* 77, 91–5.

[97] Schuurmans et al, 'Dutch GPs' Experiences of Burden by Euthanasia Requests from People with Dementia: A Quantitative Survey' (n 90) 7.

[98] Van den Ende and Asscher (n 62) 182.

[99] *An Act To Amend the Criminal Code and To Make Related Amendments To Other Acts (Medical Assistance in Dying)*, SC 2016, c 3. While MAID legislation is federal, policy and implementation falls upon the individual provinces and territories due to the division of power: Eliana Close, Jocelyn Downie and Ben P White, 'Practitioners' Experiences with 2021 Amendments to Canada's Medical Assistance in Dying Law' (2023) 17 *Palliative Care and Social Practice* 1, 5, 10.

[100] *Criminal Code*, RSC 1985, c C-46, s 241.2(1)(c) ('Canada *Criminal Code*').

[101] Ibid s 241.2(2)(a).

[102] Ibid s 241.2(2)(b).

acceptable.'[103] In addition, the request for assisted dying must be voluntary.[104] In general, death does not have to be reasonably foreseeable for a person to access assisted dying in Canada.[105] Two tracks with different access requirements exist depending on whether death is or is not reasonably foreseeable. What this means for persons with dementia wishing to access assisted dying in Canada is considered below.

(a) Access during the Early Stages of Dementia

Dementia is a serious and incurable illness, thus satisfying this eligibility requirement of MAID. To receive MAID, a person must also have decision-making capacity.[106] As discussed in the context of the Netherlands, many persons in the early stages of dementia may still satisfy this requirement.

In addition, MAID requires persons wishing to access assisted dying to be 'in an advanced state of irreversible decline in capability'.[107] During the early stages of dementia persons may already be in a state of decline. Yet the question arises whether this state of decline can be considered 'advanced' during the early stages of the illness. Whether this is the case is open to interpretation by the respective MAID assessors and providers in each individual case. Thaddeus Mason Pope points out that while some medical practitioners see this condition satisfied in the early stages of dementia, others do not.[108]

Lastly, the dementia or state of decline must cause a person wishing to access assisted dying in Canada to endure 'physical or psychological suffering' which is 'intolerable to them and that cannot be relieved under conditions that they consider acceptable'.[109] This criterion is not further defined in legislation and is generally understood to be a subjective one determined by the individual

[103] Ibid s 241.2(2)(c). Since 2021 it is no longer a general access requirement for MAID that the person's natural death be reasonably foreseeable: *An Act To Amend the Criminal Code (Medical Assistance in Dying)*, SC 2021, c 2, cl 7.

[104] Canada *Criminal Code* (n 100) s 241.2(1)(d).

[105] Ibid s 241.2(3.1).

[106] Ibid s 241.2(1)(b). For an overview of decision-making capacity and informed consent: see generally Thomas B McMorrow, 'The Waxing & Waning of Informed Consent: Medical Assistance in Dying and the Question of Advance Requests' (2021) 58(2) *Osgoode Hall Law Journal* 287, 291–7.

[107] Canada *Criminal Code* (n 100) s 241.2(2)(b).

[108] Thaddeus Mason Pope, 'Medical Aid in Dying and Dementia Directives' (2021) 4(2) *Canadian Journal of Bioethics* 82, 83.

[109] Canada *Criminal Code* (n 100) s 241.2(2)(c).

wishing to access assisted dying.[110] Whether a person suffers intolerably must be confirmed by health practitioners in each individual case.[111] As in the Netherlands, intolerable suffering in this context can include anticipatory suffering, meaning that the person is currently suffering from fear or anxiety regarding potential future losses caused by their illness.[112]

It has been reported that in practice it can be challenging for MAID assessors to identify the point at which a person with dementia meets all access criteria while still remaining competent.[113] Ultimately, if a person with dementia in the early stages is not assessed as being in an advanced state of irreversible decline in capability and to be enduring intolerable suffering, they are ineligible for assisted dying in Canada at that stage. Indeed, while not specifically referring to cases with dementia as the underlying condition, the annual report on MAID by Health Canada for the 2023 calendar year shows that in practice some of the main reasons for rejecting MAID requests were that the person was considered not to be in an advanced state of irreversible decline or not experiencing intolerable suffering.[114]

Persons with dementia who still have capacity but who do not yet wish to access assisted dying can be reviewed periodically by a medical practitioner in order to be informed when they are likely to lose capacity in the near future.[115] If they meet all other eligibility requirements, they may choose

[110] See Hayden P Nix, 'Operationalizing the Intolerable Suffering Criterion in Advance Requests for Medical Assistance in Dying for People Living with Dementia in Canada' (2024) *Cambridge Quarterly of Healthcare Ethics* 1, 3.

[111] See generally Christopher Lyon, 'Words Matter: "Enduring Intolerable Suffering" and the Provider-Side Peril of Medical Assistance in Dying in Canada' (2024) 51(3) *Journal of Medical* Ethics 187, 188.

[112] See, eg, Canadian Association of MAiD Assessors and Providers, *Guidance on the Use of a Waiver of Final Consent* (Guideline, September 2024) 17 <https://camapcanada.ca/wp-content/uploads/Guidance-on-the-Use-of-a-Waiver-of-Final-Consent-FINAL-September-2024-edited-Jan-2025.pdf>, archived at <https://perma.cc/HRS6-W4Y2>.

[113] Rebecca Zandbergen, 'Should Dementia Patients Be Able To Make Advance Requests for Medical Assistance in Dying?', *CBC News* (online, 13 February 2024) <https://www.cbc.ca/news/canada/ottawa/dementia-patient-maid-canada-request-rules-1.7101508>, archived at <https://perma.cc/9UTJ-XTY7>.

[114] Health Canada, *Fifth Annual Report on Medical Assistance in Dying in Canada 2023* (Report, December 2024) 19–20 <https://www.canada.ca/content/dam/hc-sc/documents/services/publications/health-system-services/annual-report-medical-assistance-dying-2023/annual-report-medical-assistance-dying-2023.pdf>, archived at <https://perma.cc/2YB5-D3TG> ('*Fifth Annual Report*'). Overall, 915 persons were deemed ineligible for assisted dying in the 2023 calendar year: at 7.

[115] Canadian Association of MAiD Assessors and Providers, *Medical Assistance in Dying (MAiD) Assessments for People with Dementia* (Guideline, May 2024) 17 <https://camapcanada.ca/wp-content/uploads/Assessments-for-People-with-Dementia-FINAL-May-2024.pdf>, archived at <https://perma.cc/7M5U-UTM5>.

to access assisted dying at that point before loss of capacity prevents subsequent access.[116]

(b) Access during the Later Stages of Dementia

In Canada, persons with late-stage dementia who have lost capacity but meet all other eligibility requirements have been able to access assisted dying under certain circumstances since 2021.[117] Prior to that time, persons who wanted to die with assistance had to express final consent at the time of administration of the lethal substance and had to have capacity when doing so.[118] Consequently, persons who had lost capacity after their initial request but before the time of the administration of MAID could no longer lawfully receive assistance in dying.

This changed in 2021 with the introduction of Bill C-7, which allows the waiver of final consent for persons whose death is reasonably foreseeable and who are at risk of losing capacity, under certain circumstances.[119] That means, in order to access MAID, persons with dementia whose death is reasonably foreseeable and who meet all other eligibility requirements must have capacity when requesting MAID initially.[120] While they are still competent, they can waive final consent for MAID by making a written arrangement with their medical practitioner or nurse practitioner setting down a specific future date on or before which the practitioner will administer the assisted dying substance.[121] In this arrangement, the person consents in writing to the administration of the assisted dying substance on or before the specified day.[122] Assisted dying can then be provided by their medical or nurse practitioner as per the request even if the person has since lost capacity.[123] The Canadian

116 This is referred to as the '10 minutes to midnight approach': ibid 16–17.

117 Canada *Criminal Code* (n 100) s 241.2(3.2); Michaela Estelle Okninski and Joel Grieger, 'Evolving Law: Further Developments Concerning MAID in Canada' (2021) 18(3) *Journal of Bioethical Inquiry* 371, 372.

118 See Okninski and Grieger (n 117) 372.

119 See above n 117.

120 Canada *Criminal Code* (n 100) s 241.2(3.2)(a). The main reason why requests for MAID were considered ineligible in the 2023 calendar year was that persons were assessed as not having capacity to make decisions about their health: Health Canada, *Fifth Annual Report* (n 114) 19–20.

121 Canada *Criminal Code* (n 100) s 241.2(3.2)(a)(ii). The waiver can only be lawfully used if two independent clinicians have assessed the person as eligible: at ss 241.2(3)(a), (e), (3.2)(a)(i).

122 Ibid s 241.2(3.2)(a)(iv).

123 Ibid (n 100) s 241.2(3.2)(b); Pope (n 108) 84.

legislation therefore allows a specific type of advance consent to assisted dying[124]. The legislation does not set out what the maximum time period is during which assisted dying can be provided in future based on the final consent waiver.[125] This is left to the discretion of individual practitioners. The provision of assisted dying on the chosen day is not possible if the person refuses the administration of the substance or resists it in any way.[126] Further, the legislation does not specify whether the provider may reattempt the provision of the assisted dying substance at a later stage under these circumstances.[127] Even if they have entered into a final consent waiver, practitioners are under no obligation to provide assisted dying based on the waiver.[128]

Advance euthanasia requests which can replace a request for assisted dying and can be acted upon once a person loses capacity (as available in the Netherlands) are currently not permitted under the federal MAID legislation in Canada. Yet Quebec has allowed advance requests for MAID since 30 October 2024.[129]

2 *Access under Quebec Law*

A number of recent studies exploring the attitudes of different groups in Quebec, including the general population[130] and people living with Alzheimer's,[131] revealed that a significant number were generally supportive of extending MAID to non-competent persons with dementia based on an advance request. In June 2023, Bill 11[132] passed, amending the Quebec *Act Respecting End-of-Life Care* by allowing advance requests for MAID, which are requests 'made in

[124] Gina Bravo et al, 'Characterizing Canadian Social Workers Willing To Be Involved in Medical Assistance in Dying for Persons Lacking Decisional Capacity' (2024) 67(1) *Journal of Gerontological Social Work* 19, 20.

[125] McMorrow (n 106) 330.

[126] Canada *Criminal Code* (n 100) s 241.2(3.2)(c).

[127] McMorrow (n 106) 330.

[128] See Pope (n 108) 84.

[129] 'Quebec To Approve Advance Requests for MAID as of Oct 30', *CBC News* (online, 7 September 2024) <https://www.cbc.ca/news/canada/montreal/quebec-advance-requests-maid-1.7316668>, archived at <https://perma.cc/EV3N-GVAE>.

[130] See A Plaisance et al, 'Quebec Population Highly Supportive of Extending Medical Aid in Dying to Incapacitated Persons and People Suffering Only from a Mental Illness: Content Analysis of Attitudes and Representations' (2022) 21 *Ethics, Medicine and Public Health* 100759:1–9, 3, 6.

[131] See Vincent Thériault, Diane Guay and Gina Bravo, 'Extending Medical Aid in Dying to Incompetent Patients: A Qualitative Descriptive Study of the Attitudes of People Living with Alzheimer's Disease in Quebec' (2021) 4(2) *Canadian Journal of Bioethics* 69, 70, 73.

[132] Bill 11, *An Act To Amend the Act Respecting End-of-Life Care and Other Legislative Provisions*, 1st sess, 43rd leg, Quebec, 2023.

anticipation of a person becoming incapable of giving consent to care, with a view to an administration of such aid after the onset of that incapacity'.[133] The law commenced operation on 30 October 2024.[134]

When a person makes an advance request for assisted dying they must meet certain criteria, including being 'capable of giving consent to care' and suffering from 'a serious and incurable illness leading to incapacity to give consent to care'.[135] As per Quebec law, an advance request for MAID must be made in the prescribed form[136] and with the assistance of a specific physician or nurse practitioner.[137] The request form can include up to two trusted parties, referred to as trusted third persons, who will ensure that health practitioners are aware of the existence of the advance request and of any change in circumstances.[138] The request must include a detailed description of the specific symptoms based on which the non-competent person wishes to receive assisted dying.[139] The request must then be signed in the presence of the medical or nurse practitioner assisting the person, two witnesses and any named trusted third persons.[140] The request must also be recorded in a register kept by the Minister.[141]

At the time MAID is to be administered based on the advance request, the person must be incapable of giving consent to care due to their illness, be in an advanced state of irreversible decline in capability, exhibit the symptoms described in the request and experience 'enduring and unbearable physical or psychological suffering that cannot be relieved under conditions considered tolerable'.[142] Prior to administering MAID, a second practitioner must confirm

133 *Act Respecting End-of-Life Care*, RSQ 2014, c S-32.0001, s 25.1.

134 Health practitioners providing MAID based on an advance directive in Quebec are in violation of federal criminal law which permits providing MAID generally only to persons who have decision-making capacity and can consent to MAID immediately prior to administration. This is not the case where a person is no longer competent: see above Part II F 1(b). However, it has been reported that the Minister of Justice of Quebec has asked the Quebec prosecution service not to prosecute health practitioners in these cases: 'Quebec to Approve Advance Requests for MAID as of Oct 30' (n 129).

135 *Act Respecting End-of-Life Care* (n 133) ss 29.1(1)(a), (c).

136 Ibid s 29.2.

137 Ibid s 29.3.

138 Ibid s 29.6.

139 Ibid s 29.3.

140 Ibid ss 29.7–29.8.

141 Ibid ss 29.10, 63.

142 Ibid s 29.1(2).

that all criteria have been met.[143] If the person expresses refusal to receive assisted dying, the lethal substance cannot be provided.[144]

While some persons with dementia are eligible for assisted dying in Canada, the section below considers how frequently this is provided in practice.

3 *Access in Practice*

According to the *Fifth Annual Report* from Health Canada, in the 2023 calendar year, assisted dying was provided in Canada in 15,343 cases.[145] Overall, 241 individuals who received MAID had dementia. It was the sole underlying condition in 106 cases.[146] In total 76.4 per cent of people with dementia who received MAID did so under Track 1 (natural death is reasonably foreseeable) while 23.6 per cent received assisted dying under Track 2 (natural death is not reasonably foreseeable).[147] Assisted dying was provided based on a final consent waiver in 594 instances.[148] The report does not break down further, however, in how many cases MAID was provided to a person with dementia based on a final consent. The report did not raise any concerns with the provision of MAID to persons with dementia in the 2023 calendar year.[149]

4 *Analysis: Access to Assisted Dying for Persons with Dementia in Canada*

The above shows that persons with dementia may be able to access MAID both during the early and late stages of the illness depending on their individual circumstances. Yet the following legal and practical access barriers for persons with dementia exist in the Canadian context.

(a) Interpretation of the Legislative Framework

One access hurdle to assisted dying for persons with dementia in Canada may be practitioners' differing interpretations of eligibility criteria enshrined in the legislative framework.

(i) Advanced State of Decline and Intolerable Suffering

Persons with dementia may access MAID in the early stages of the illness when they still have capacity. Yet a person wanting to die with assistance needs to be 'in an advanced state of irreversible decline in capability'. The law does not

143 Ibid s 29.19.

144 Ibid.

145 Health Canada, *Fifth Annual Report* (n 114) 7.

146 Ibid 29.

147 Ibid 11, 29.

148 Ibid 57.

149 See ibid 29.

define this criterion further and there are no federal guidelines for practitioners providing further clarification as to when this could be the case. Yet individual organisations provide interpretation guidelines.[150] The Canadian Association of MAiD Assessors and Providers, for example, points out that in order to determine whether a person with dementia is in an advanced state, it is necessary to identify 'the amount of cognitive decline that has occurred from baseline but also to the absolute degree of the patient's decline and the state in which the person now finds themselves'.[151] Different practitioners may reach different conclusions regarding this requirement where persons are in the early stages of dementia. This may also be the case concerning the assessment of whether a person is suffering intolerably in the early stages of the illness. Varying interpretations of the law may lead to inequitable access in practice.

(ii) Death Reasonably Foreseeable for Final Consent Waiver

In order to enter into a final consent waiver in cases where persons are likely to lose capacity, a person must meet all eligibility criteria, including having decision-making capacity when requesting MAID and waiving final consent. At the same time, their death must be reasonably foreseeable. The law does not further define when death is reasonably foreseeable. Health Canada notes that a person must be 'approaching the end of their life in the near term'.[152] Yet the Canadian Association of MAiD Assessors and Providers points out that 'reasonably foreseeable' has the meaning of 'reasonably predictable', concluding that '[t]his may mean that there is sufficient temporal proximity to death (it is coming soon), and/or that the trajectory towards death is predictable from the person's combination of known medical conditions and potential sequelae'.[153] In terms of dementia, the Association concludes that 'the primary dementias have

[150] Close, Downie and White (n 99) 13. See, eg, 'CAMAP Publications and Guidelines', *Canadian Association of MAiD Assessors and Providers* (Web Page) <https://camapcanada.ca/for_clinicians/publications/>, archived at <https://perma.cc/W4F7-L38F>.

[151] Canadian Association of MAiD Assessors and Providers, *Medical Assistance in Dying (MAiD) in Dementia* (Report, 2022) 12 <https://camapcanada.ca/wp-content/uploads/2022/02/Assessing-MAiD-in-Dementia-FINAL-Formatted.pdf>, archived at <https://perma.cc/347J-EPPA>.

[152] 'Medical Assistance in Dying: Implementing the Framework', *Health Canada* (Web Page, 30 July 2024) <https://www.canada.ca/en/health-canada/services/health-services-benefits/medical-assistance-dying/implementing-framework.html>, archived at <https://perma.cc/6SZX-76FX>.

[153] Canadian Association of MAiD Assessors and Providers, *The Interpretation and Role of 'Reasonably Foreseeable' in MAiD Practice* (Guidelines, February 2022) 1 <https://camapcanada.ca/wp-content/uploads/2022/03/The-Interpretation-and-Role-of-22Reasonably-Foreseeable22-in-MAiD-Practice-Feb-2022.pdf>, archived at <https://perma.cc/C9UK-5YLZ>.

shortened life expectancies; they are ultimately fatal. Thus, death is reasonably predictable and is therefore reasonably foreseeable.'[154]

While some practitioners may consider the death of persons who are likely years from dying reasonably foreseeable, others may consider this only to be the case where persons are closer to dying.[155] As such, and depending on the interpretation of this requirement by an individual medical or nurse practitioner, some persons living with dementia may be able to waive final consent for assisted dying while they still have capacity as their death is considered reasonably foreseeable, while others may not.

(iii) Timeframe for the Final Consent Waiver

In addition, the legislation does not provide timeframes regarding how far in advance the date for the provision of MAID can be set in a final consent waiver.[156] The law does specify, however, that a person must be at risk of losing capacity to enter into a final consent waiver. In a study published in 2023 on practitioners' experiences with the 2021 assisted dying amendments in Canada, Eliana Close, Jocelyn Downie and Ben P White found that some Canadian practitioners were amenable to selecting a date up to a year in the future while others were inclined to select a date only some months away or less.[157] Some practitioners expressed concern that agreeing to a date in the distant future would ultimately turn the final consent waiver into an AED, which they believed to be unintended by the law.[158] Practitioners who are unsure of how to interpret the legislation may be less willing to enter into a final consent waiver and subsequently perform assisted dying due to the risk of possible future legal consequences.[159]

Publishing further guidance on the requirements enshrined in the legislative framework may increase practitioners' confidence in interpreting and complying with the law, streamlining practitioners' assessments and providing more equitable access to assisted dying in practice.

Apart from legal uncertainties, there may be other reasons causing MAID assessors and providers to be reluctant in providing assisted dying for persons with dementia, especially once persons have lost capacity.

[154] Canadian Association of MAiD Assessors and Providers, *Medical Assistance in Dying (MAiD) Assessments for People with Dementia* (n 115) 16.

[155] Pope (n 108) 84.

[156] McMorrow (n 106) 330.

[157] Close, Downie and White (n 99) 15.

[158] Ibid 10.

[159] See also ibid 12–13.

(b) Moral and Ethical Objections

Practitioners' moral and ethical objections have been identified as one hurdle to providing assisted dying to persons with dementia in Canada, especially where this is based on a final consent waiver. For example, a 2022 study by Caroline Variath and colleagues found that Canadian healthcare providers can feel greater 'moral distress' when asked to provide MAID where persons no longer have capacity to consent to assisted dying.[160] Moreover, several recent studies have highlighted healthcare workers' reluctance in providing MAID in cases where persons did not appear to be suffering after losing capacity irrespective of a previous final consent waiver agreement.[161]

(c) Complexity and Lack of Support

There are also practical concerns with providing assisted dying based on a final consent waiver. Some Canadian practitioners identified a lack of resources when making these highly complex and difficult decisions[162] and the related potential increase in workload[163] as a hurdle to providing assisted dying to persons with dementia.

(d) Access Hurdles in Quebec

As the Quebec law allowing advance requests for MAID has only recently commenced operation, it is unclear at this point whether hurdles will arise that prevent healthcare professionals from providing assisted dying to non-competent persons with dementia.[164] However, several recent Canadian studies on the attitudes of practitioners in providing MAID to persons with dementia based on an advance directive have documented practitioners' concerns[165] and highlighted perceived ethical and logistical difficulties in this space.[166] As such, it

160 Caroline Variath et al, 'Health Care Providers' Ethical Perspectives on Waiver of Final Consent for Medical Assistance in Dying (MAiD): A Qualitative Study' (2022) 23 *BMC Medical Ethics* 8:1–14, 11.

161 See, eg, ibid 9; Close, Downie and White (n 99) 15.

162 Final consent waiver resources varied between jurisdictions and locations: Close, Downie and White (n 99) 12–13.

163 Variath et al (n 160) 10–11.

164 See above n 134 and accompanying text.

165 Concluding that there is a 'gap between public desire for, and practitioner willingness to provide MAiD in dementia': Adrian C Byram et al, 'Advance Requests for MAiD in Dementia: Policy Implications from Survey of Canadian Public and MAiD Practitioners' [2021] (June) *Canadian Health Policy Journal* 1, 1.

166 Allison Nakanishi, Lauren Cuthbertson and Jocelyn Chase, 'Advance Requests for Medical Assistance in Dying in Dementia: A Survey Study of Dementia Care Specialists' (2021) 24(2)

remains to be seen whether the Quebec experience with advance requests for MAID for non-competent persons with dementia will mirror the Dutch experience.

In light of the models in the two jurisdictions including the identified access hurdles the below considers how Australian VAD laws would have to be reformed to grant persons with dementia access to assisted dying at different stages should Australian states elect to do so.

III Required Changes to Australian VAD Laws if Permitting Access for Persons with Dementia

A *Concurrent Requests for VAD*

To allow persons with dementia to make concurrent requests for assisted dying, the following aspects of Australian VAD laws require reform.

1 *Advanced Terminal Illness and Timeframe until Expected Death*

There are no timeframe-until-death restrictions in the two analysed international jurisdictions, which is why persons with dementia in the early stages are not prevented from accessing assisted dying in the Netherlands and Canada. However, all VAD laws in Australian states currently require a person wishing to access assisted dying to suffer from a terminal illness which must be advanced and progressive and expected to cause death within a specific timeframe — in the case of dementia, no more than 12 months.[167] As pointed out above,[168] persons with dementia are unlikely to meet this requirement during the early stages of the illness.[169] Granting persons living with dementia access to VAD

Canadian Geriatrics Journal 82, 82, 89. For analysis on the potential difficulties of assessing intolerable suffering based on an advance request: see also 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, 2018) 72, 144–5 <https://cca-reports.ca/wp-content/uploads/2019/02/The-State-of-Knowledge-on-Advance-Requests-for-Medical-Assistance-in-Dying.pdf>, archived at <https://perma.cc/AVY8-4X62>.

[167] See above Part II B .

[168] See above Part II C .

[169] For discussion on how stopping eating and drinking may make persons with dementia in the early stages eligible for assisted dying based on dehydration as a terminal illness in the US context: Thaddeus Mason Pope and Lisa Brodoff, 'Medical Aid in Dying To Avoid Late-Stage Dementia' (2024) 72(4) *Journal of the American Geriatrics Society* 1216, 1218–20.

during the early stages of the illness requires removing the timeframe-until-death access restrictions from VAD laws.[170]

Yet this alone may not be sufficient to enable access to VAD for persons with dementia. Even if the timeframe-until-death restrictions were removed, Australian VAD laws would continue to require persons to suffer from a terminal illness which must be advanced.[171] While dementia is a terminal illness, a person living with dementia in the early stages — who may still be many years away from expected death — may not be considered to be suffering from an advanced terminal illness at that stage. Neither international jurisdiction analysed in this article requires persons to suffer from an advanced terminal illness to access assisted dying. In Australian states, the requirement that the terminal illness must be advanced may have to be removed should access be desired for persons with dementia in the early stages.

Instead of having an advanced terminal illness, the Canadian law requires a person to be in 'in an advanced state of irreversible decline in capability'.[172] Should such a criterion be contemplated in Australian VAD laws for persons with dementia, instead of requiring them to have an advanced terminal illness, care should be taken to ensure that the guidelines published by Australian states to support compliance with VAD laws define this criterion further to ensure streamlined interpretation in practice.[173]

2 *Intolerable Suffering*

Both analysed international jurisdictions require persons to suffer to a certain degree: lasting and unbearable suffering with no reasonable alternatives in the Netherlands[174] and intolerable suffering that cannot be relieved under

[170] As discussed above, the NSW *VAD Act* (n 7) explicitly prevents access to VAD based solely on dementia: at s 16(2)(b). This would require amendment if access for persons with dementia was desired.

[171] NSW *VAD Act* (n 7) s 16(1)(d); Qld *VAD Act* (n 7) s 10(1)(a); SA *VAD Act* (n 7) ss 26(1)(d), (4); Tas *VAD Act* (n 7) ss 6(1), 10(1)(e); Vic *VAD Act* (n 7) s 9(1)(d); WA *VAD Act* (n 7) s 16(1)(c). The ACT *VAD Act* (n 14) does not contain a timeframe-until-death access restriction. It nevertheless requires the terminal illness to be advanced meaning that a person must be approaching the end of their life: at s 11(3)(c).

[172] See above n 102.

[173] For published guidelines: see, eg, Queensland Health, *Queensland Voluntary Assisted Dying Handbook: Version 2.0* (Handbook, October 2022) <https://www.health.qld.gov.au/__data/assets/pdf_file/0027/1166184/qvad-handbook.pdf>, archived at <https://perma.cc/Y5U5-AFZC>.

[174] See above Part II E .

conditions the person finds acceptable in Canada.[175] Australian VAD laws currently require a person to suffer in a way they find intolerable.[176]

Persons in the early stages of dementia may not yet be considered to suffer intolerably as the symptoms associated with severe dementia may not have occurred at this point. They may, however, suffer psychologically due to fear of future suffering. The *2022 Euthanasia Code* in the Netherlands, for example, suggests that assessors can consider the fear of future suffering and decline in the assessment concerning the current suffering of persons living with dementia.[177]

Should Australian jurisdictions desire to give competent persons with dementia the choice to access VAD, care would have to be taken to ensure that access is not infringed by requiring a degree of suffering that is not necessarily associated with dementia in the early stages. To do so, potential future legislation could specify that the suffering required for VAD access could also be caused by the anticipation of future suffering from the medical condition. This is already the case more generally in the ACT, where the VAD law sets out that individuals suffer intolerably if 'persistent suffering (whether physical, mental or both) is being caused' amongst others by the 'anticipation or expectation, based on medical advice, of suffering that will or might be caused' by the condition or its treatment.[178]

B *Advance Requests for VAD*

In addition, Australian jurisdictions may elect to allow non-competent persons with dementia access to assisted dying in future. To do so, Australian VAD laws require reform.

All current Australian VAD laws require a person to have decision-making capacity at all stages of the VAD process.[179] To grant access to persons with dementia in the later stages once they have lost capacity, this restriction would have to be modified. This has been done in different ways in the two jurisdictions analysed in this article. In Canada, a person who has lost capacity may be able to receive assisted dying if they have entered into a final consent waiver

[175] See above Part II F 1).

[176] See above n 35 and accompanying text.

[177] *2022 Euthanasia Code* (n 55) 23.

[178] ACT *VAD Act* (n 14) ss 11(4)(a)(i)–(ii). Anticipation of suffering is also included in the Tas *VAD Act* (n 7) s 14(b)(ii).

[179] See above n 36.

with their practitioner.[180] In the Netherlands[181] and Quebec,[182] a non-competent person may receive assisted dying based on an AED or advance request. How each approach would translate into the Australian context is considered below.

1 *Waiver*

To access MAID in Canada, a person must make one written request for MAID which must be signed by an independent witness.[183] In addition, they must provide final consent before receiving assistance in dying.[184] A person must generally have capacity during all stages of the process, including during final consent.[185] Yet persons who are at risk of losing capacity, including persons with dementia, can waive final consent for assisted dying.[186] They must, however, meet all eligibility criteria including having capacity when requesting assisted dying and waiving final consent.[187]

(a) Content of Waiver in the Australian Context

In Australian states, and differently from the situation in Canada, a person must make three requests for assisted dying, including one written request which must be witnessed.[188] Should assisted dying for non-competent persons be desired, future Australian VAD laws could set out, for example, that a person who is at risk of losing capacity and meets all other requirements (including having decision-making capacity) is able to waive the requirement that they continue to remain competent after their final approval for VAD access.[189] This would mean that a competent person with dementia who has requested VAD three

[180] See above Part II F 1(b).

[181] See above Part II E 2).

[182] See above Part II F 2).

[183] Canada *Criminal Code* (n 100) ss 241.2(3)(b)–(c).

[184] Ibid ss 241.2(3)(h), (3.1)(k).

[185] Ibid ss 241.2(1)(b), (3)(a), (h), (3.1)(a), (k).

[186] Ibid s 241.2(3.2).

[187] Ibid s 241.2(3.2)(a).

[188] NSW *VAD Act* (n 7) ss 19, 43, 48; Qld *VAD Act* (n 7) ss 14, 37, 42; SA *VAD Act* (n 7) ss 29, 52, 55; Tas *VAD Act* (n 7) ss 18, 30, 53; Vic *VAD Act* (n 7) ss 11, 34, 37; WA *VAD Act* (n 7) ss 18, 42, 47.

[189] The ACT Legislative Assembly has called on the ACT Government to 'explore the issue experienced in other VAD jurisdictions of ineligibility due to loss of capacity following the final approval for VAD access': Australian Capital Territory, *Notice Paper No 121*, Legislative Assembly, 4 June 2024, 1987 (Marisa Paterson) <https://www.parliament.act.gov.au/__data/assets/pdf_file/0009/2462904/NP-121-4-June-2024.pdf>, archived at <https://perma.cc/SPF6-CR2A>.

times and received final approval for VAD may still receive assisted dying on or before the date set down in the agreement with their practitioner even if they have lost capacity since.

(b) Eligibility Criteria at the Time of Waiver

The Canadian law only allows a final consent waiver in cases where a person's death is reasonably foreseeable.[190] As pointed out above, some medical practitioners in Canada consider a person's death reasonably foreseeable when they are still years from their expected death. This far out from death, persons living with dementia are likely still competent and may be able to waive final consent. In Australia, however, according to current state VAD laws, a person must be no more than 12 months from expected death to access VAD. Should future Australian frameworks require persons with dementia to be no more than 12 months from dying and competent when entering into a waiver of capacity, only very few people with dementia would be able to do so. As raised above for concurrent requests, removing the timeframe-until-expected-death requirement is also necessary if Australian states wish to allow non-competent persons with dementia access to VAD in future, including the opportunity to make a capacity waiver for the remainder of the process.

(c) Timeframe for the Provision of Assisted Dying after Waiver

As analysed above, the Canadian framework contains no timeframe during which the date for assisted dying based on a final consent waiver must occur. Due to this lack of regulation, some people may be able to agree on a date for assisted dying up to a year in advance while others may only be able to agree on a date in the near future. To avoid such discrepancies in the Australian context, a potential future framework in Australian states should include guidance as to how far in advance a date for assisted dying can be set.

(d) Refusal and Resistance on the Day

Another issue a future Australian framework would have to address is how to respond to the situation where a person waives the capacity requirement for the remainder of the VAD process but then refuses assisted dying on the day of provision, when they are no longer competent. The Canadian legal framework explicitly sets out that assisted dying cannot be provided where a person displays resistance or refusal on the day.[191] Should this also be adopted in a future Australian law, this would mean that persons may not be able to receive the

[190] Canada *Criminal Code* (n 100) s 241.2(3.2).

[191] Ibid s 241.2(3.2)(c).

type of death they envisioned and set out in their waiver agreement while still competent. Differently from the Canadian framework, however, future Australian laws should clarify what the consequences would be where a person resists the provision of assisted dying. Legislation should set out whether a practitioner can reattempt the administration at a later stage or whether assisted dying can no longer be provided once a non-competent person refuses the administration.

(e) Moral Issues, Complexity and Lack of Support Concerning Waivers

In the Canadian context, moral and practical hurdles to the provision of assisted dying to persons with dementia based on a final consent waiver have been identified. These include concerns about the lack of resources and support in the assessment of these complex cases and moral concerns about providing assisted dying to persons who are no longer able to confirm that they are wanting to end their life with assistance.[192] It is likely that similar issues could arise in the Australian context should assisted dying be permitted based on a waiver for persons with dementia who have lost capacity.

Lack of support and complexity of assessments could be addressed in the Australian context through resourcing, additional training and the development of specific guidelines in relation to VAD for persons with dementia. Yet this does not automatically mean that there will be a sufficient number of medical practitioners willing to provide assisted dying to persons with dementia, especially those who have lost capacity.[193] In contrast to Canada and the Netherlands, it is currently unclear what medical practitioners' attitudes are to expanding VAD to non-competent persons with dementia in the Australian context, as no research has explored this question to date. It is easy to imagine, however, that some practitioners may have the same moral and ethical concerns as described by some Canadian practitioners about administering a lethal substance to a non-competent person who is no longer able to confirm that they are wanting to die with assistance. Already, persons wishing to access VAD in Australian states are reporting issues with finding medical practitioners who are VAD-qualified and willing to participate in the assisted dying process.[194]

[192] See above Part II F 4(b)–(c).

[193] For general discussion on the challenges of identifying qualified medical practitioners willing to provide assistance in dying, see: Marcus Sellars et al, 'Medical Practitioners' Views and Experiences of Being Involved in Assisted Dying in Victoria, Australia: A Qualitative Interview Study among Participating Doctors' (2022) 292 *Social Science and Medicine* 114568:1–9, 1–2.

[194] Go Gentle Australia, *State of VAD: Voluntary Assisted Dying in Australia & New Zealand 2024* (Report, 2024) 26–7 <https://assets.nationbuilder.com/gogentleaustralia/pages/3038/attachments/original/1723682650/GGA_StateOfVAD_Report_2024_DIGITAL_Aug24.pdf?1723682650>, archived at <https://perma.cc/AH4Y-ZDF5>.

Due to the aging Australian population and the increase in conditions resulting in capacity loss,[195] there may be more persons with dementia wanting to enter into a waiver — should this become available — than practitioners willing to assist in these cases. This could mean that some persons with dementia wanting to be provided with assisted dying based on a waiver once they have lost capacity may not be able to arrange and receive this.[196] To make an informed decision, patients would have to be advised about their potentially low chances of receiving assisted dying based on a waiver once they lose capacity.

The Dutch framework allows for assisted dying for non-competent persons with dementia based on an AED.[197] This has also become possible in Quebec since late October 2024.[198] The following would have to be considered should Australian states wish to adopt an AED model in future.

2 *Advance Euthanasia Directive/Advance Request*

(a) Request Process

In the Netherlands, a person can make an AED setting out the future circumstances under which they wish to receive assistance in dying once they lose capacity.[199] If all other due care criteria are met, a non-competent person can die with assistance. A person must only make one request for assisted dying in the Netherlands and the AED can replace a verbal request once a person has lost capacity. Advance requests for assisted dying have also recently become available in Quebec. There, a person must generally make one written request for assisted dying and provide final consent at the time of administration. The advance request replaces both the request and the provision of final consent in Quebec.

In Australian states, a person must make three requests for assisted dying with at least one written request witnessed by two witnesses who must meet certain criteria.[200] Permitting AEDs in the Australian context would likely mean that all three requests currently required for assisted dying would be replaced by one advance directive. As such, the multiple-request safeguard would no longer exist in the case of non-competent persons with dementia, which

195 Australian Bureau of Statistics, *Population Projections, Australia* (Catalogue No 3222.0, 23 November 2023) <https://www.abs.gov.au/statistics/people/population/population-projections-australia/latest-release>, archived at.<https://perma.cc/G4BX-4V7S>. See above nn 3, 18.

196 For similar concerns regarding advance directives: McMorrow (n 106) 331–2.

197 See above Part II E .

198 See above Part II F 2).

199 *Termination of Life Act* (n 46) art 2(2). See above n 64.

200 See above n 188 and accompanying text.

could potentially increase the risk of a person receiving VAD against their will. To increase the protection of vulnerable individuals during this process, additional safeguards could be introduced. For example, persons could be required to make the advance directive with the assistance of a medical practitioner in front of witnesses and, if desired, by including trusted third parties and subsequently registering it in a central register (as is the case in Quebec). In comparison, in the Netherlands, an AED requires no specific form or registration and does not have to be witnessed or made with the assistance of a medical practitioner.

Even when adopting a stricter request protocol such as the one in place in Quebec, however, some of the current safeguards enshrined in Australian VAD laws will not be in operation when VAD is provided to non-competent persons with dementia based on an advance directive. The question of whether allowing AEDs in Australian states decreases safety in the context of assisted dying to a degree that is unacceptable requires detailed consideration in the context of future law reform.

(b) Moral Issues, Complexity and Lack of Support

Allowing an AED to replace the requests for VAD once a person becomes non-competent could theoretically give persons living with dementia the most extensive level of access to VAD during the late stages. However, the experience in the Netherlands shows that the law does not necessarily translate well into practice. Studies have highlighted that it can be challenging for doctors in the Netherlands to interpret whether a non-competent person with dementia is suffering to the required degree and consequently whether they can lawfully provide assisted dying. Some doctors have noted moral and ethical concerns as a reason for not providing assisted dying based on an AED. A number of Dutch healthcare providers also considered the lack of training and support in making these complex assessments a reason not to participate.[201] The result is that, in practice, very few people in the Netherlands receive assisted dying based on an AED. Some scholars therefore conclude that the Dutch law 'creates a mostly theoretical option' when it comes to assisted dying in advanced dementia.[202]

It is to be expected that medical practitioners in Australian states would face some of the same difficulties as their Dutch colleagues in the context of providing assisted dying to persons with advanced dementia. Providing additional training, resourcing and guidelines concerning eligibility assessments for non-competent persons with dementia may assist some doctors in providing

[201] See above Part II E 4).

[202] Van den Ende and Asscher (n 62) 184.

assisted dying in this context. Yet the moral concerns noted by some practitioners in the Netherlands raise questions as to whether enough Australian practitioners would be willing to participate in cases where assisted dying is based on an AED. Should AEDs be permitted in Australia in future, patients may have to be advised that although legally possible, the chances of obtaining assistance in dying in advanced dementia in practice may be very low.[203] This would ensure that persons with dementia do not forgo the opportunity to receive assisted dying in the earlier stages of the illness while they are still competent due to the belief that assisted dying will be provided to them based on an AED once they lose capacity.

IV Conclusion

With an increasing number of Australians living with dementia, calls have been made to provide individuals with a choice regarding end-of-life decisions including assisted dying. The aim of the article was not to analyse whether Australian jurisdictions should allow persons with dementia access to VAD but to outline how current Australian VAD laws would have to be reformed should states wish to permit persons with dementia access to assisted dying at different stages of the illness.

To do so, this article analysed the legal frameworks in two jurisdictions allowing persons with dementia access to assisted dying to varying degrees: the Netherlands and Canada. The article examined the different legislative frameworks and identified potential access hurdles for persons with dementia. Based on the models and experiences in these jurisdictions, the article subsequently identified specific access requirements enshrined in Australian VAD laws in need of reform should access be permitted for persons with dementia. These are: advanced terminal illness and timeframe-until-death restriction, intolerable suffering and decision-making capacity at all stages of the process.

Paul A Komesaroff and colleagues argue in the context of VAD and dementia that 'a radical revision of the VAD framework that supplants the three principles established through sustained and meticulous social consultation and debate may put at risk the fragile social compact on which it has come to rest'.[204] They comment further that 'safeguards built into all legislative frameworks

[203] This approach has been suggested in the Dutch context: van den Ende and Asscher (n 62) 185. See also Jaap Schuurmans et al, 'Supporting GPs around Euthanasia Requests from People with Dementia: A Qualitative Analysis of Dutch Nominal Group Meetings' (2020) 70(700) *British Journal of General Practice* e833, finding that Dutch practitioners highlight the need for a public campaign and brochures on assisted dying for persons with dementia clarifying that requesting assisted dying does not automatically mean that doctors will provide it: at e836–7.

[204] Komesaroff et al (n 15) 453.

across Australia were devised to offer reassurance to those who remained uncertain, and to provide an assurance that no incremental extension, or "slippery slope", would occur'.[205] On this basis, they conclude that 'the success of the VAD regimes already operating across the country depends critically on the respectful acknowledgement of contending points of view and assurances that agreed boundaries will not be crossed'.[206] Yet it cannot be overlooked that assisted dying laws can and do change over time. Principles and safeguards, once agreed upon, are subsequently amended or removed. For example, in Canada, at the federal level, final consent waivers were introduced in 2021; further, Quebec is now allowing advance requests for assisted dying. In addition, the 2024 ACT assisted dying legislation no longer imposes a timeframe-until-death eligibility requirement,[207] though this had been considered an important safeguard in all previously enacted Australian VAD laws. As the number of Australians living with dementia constantly increases, so too will calls for autonomy concerning their end-of-life decisions, including access to VAD. It does not seem unrealistic that in future, Australian states will contemplate how to reform their VAD laws to allow access for persons who are no longer competent, including persons living with dementia. This is already the case to some degree in the ACT, where since 2024 the ACT government has been exploring 'the issue experienced in other VAD jurisdictions of ineligibility due to loss of capacity following the final approval for VAD access'.[208] In order to make a decision as to whether persons with dementia should be granted access to VAD in Australia, it is necessary to identify how such a framework would have to be shaped. This question was the key focus of this article.

While this article considered what aspects of current VAD laws require reform, more research — including research on medical practitioners' attitudes towards providing VAD to persons with dementia at different stages of the illness — is necessary to identify whether access can be provided in an ethical manner while safeguarding vulnerable individuals in the Australian context.

[205] Ibid.

[206] Ibid.

[207] ACT *VAD Act* (n 14) s 11(6).

[208] Australian Capital Territory Legislative Assembly (n 189) 1987 (Marisa Paterson).