

Review of the  
*Voluntary Assisted Dying Act 2019 (WA):*  
Research Report



Lindy Willmott | Ben P White | Casey M Haining

July 2024

## Further enquiries

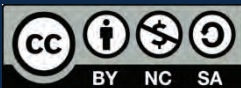
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**July 2024**

# Project team

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This Report has been prepared by a Queensland University of Technology (QUT) Project Team from the Australian Centre for Health Law Research, Faculty of Business and Law. This Project was led by Professors Lindy Willmott and Ben White. Research support was provided by Casey Haining, who was appointed as a Research Fellow for the Project. The contents of this Report and the recommendations made, represent the views of the three authors and not those of the Australian Centre for Health Law Research, the Faculty of Business and Law or QUT.

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He co-leads, alongside Professor Willmott, the end-of-life program with the Australian Centre for Health Law Research, QUT. He has been part of interdisciplinary teams that have been awarded \$65 million in the field of end-of-life decision-making. He, alongside Professor Willmott, developed the legislatively mandated VAD training in Victoria, Western Australia and Queensland. He co-leads a team that has established clinical training and resources for clinicians in the wider end-of-life context, including End of Life Law for Clinicians and End of Life Law in Australia. He also contributes to the End of Life Direction for Aged Care project.

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## Acknowledgments

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# Preface

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The *Voluntary Assisted Dying Act 2019 (WA)* was passed in December 2019, and came into effect on 1 July 2021 following an 18-month implementation period. The Act obliges the Minister for Health to “review the operation and effectiveness” of the Act at set intervals, with the first review occurring as soon as practicable after the 2nd anniversary of the Act’s operation.<sup>1</sup> An independent three-person panel (Panel), comprising Dr Elissa Campbell, Dr Sally Talbot MLC and Dr Simon Towler, were appointed by the Minister to conduct the Review.

The Panel’s terms of reference require it to consider:

- the effectiveness and the operation of the Act, as passed by the Parliament in 2019, in providing for and regulating access to voluntary assisted dying (VAD); and
- the extent to which current processes provided under the Act are operating to support persons eligible for VAD in Western Australia.

The Panel’s terms of reference state that the Review was not seeking feedback on whether VAD should be precluded or whether there should be changes to eligibility criteria for patients or practitioners involved in the VAD process.<sup>2</sup>

The Review comprised a two-stage consultation process. Stage One of the Review was managed by the Department of Health on behalf of the Panel. Stage One invited key stakeholders to complete an online survey intended to identify the most significant issues. The online survey was open between 10 November and 8 December 2023.

A research team from the Australian Centre for Health Law Research, Queensland University of Technology were engaged by the Western Australian Department of Health to carry out Stage Two of the Review. Stage Two involved carrying out targeted interviews and focus groups to explore some of the main issues captured in Stage One. Data was analysed using thematic analysis and has been reported on in this Research Report.

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<sup>1</sup> *Voluntary Assisted Dying Act 2019 (WA)* s 164.

<sup>2</sup> Department of Health, *Voluntary Assisted Dying 2019 Review* (Government of Western Australia, 2023) <<https://consultation.health.wa.gov.au/ced-clr-vad/vad-act-review/>>.

# Abbreviations

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<b>DoH</b>	Department of Health
<b>GP</b>	General Practitioner
<b>IV</b>	Intravenous
<b>MCCD</b>	Medical Certificate of Cause of Death
<b>NG</b>	Nasogastric
<b>PEG</b>	Percutaneous Endoscopic Gastrostomy
<b>QUT</b>	Queensland University of Technology
<b>RASS</b>	Regional Access Support Scheme
<b>SWCNS</b>	Statewide Care Navigator Service
<b>SWPS</b>	Statewide Pharmacy Service
<b>VAD</b>	Voluntary assisted dying
<b>VAD-IMS</b>	Voluntary Assisted Dying Information Management System
<b>WA</b>	Western Australia; Western Australian
<b>WASAT</b>	Western Australian State Administrative Tribunal
<b>WA VAD Act</b>	<i>Voluntary Assisted Dying Act 2019 (WA)</i>

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# Executive summary

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This Research Report is intended to inform the Panel's Review of the operation and effectiveness of VAD in Western Australia (WA). It reports the results of a thematic analysis of semi-structured interviews and focus groups carried out by the authors across multiple stakeholder groups, and other relevant evidence.

Overall, the authors' analysis revealed that, subject to some significant issues that need to be addressed, the VAD system in WA appears to be working well once a patient is connected to the system. The availability of VAD as another end-of-life choice has provided great comfort to patients. An emphatic finding that resonated across all stakeholder groups is the commitment of the VAD workforce including the statewide services and VAD Coordinators to person-centred care, and the pivotal role that the workforce has played in the success of the VAD scheme in WA.

Beyond these global and important perspectives, participants raised many issues relevant to the operation and effectiveness of the *Voluntary Assisted Dying Act 2019 (WA)*, which are comprehensively outlined in this Research Report. The Report makes recommendations in relation to key identified issues. The authors then provide the Panel with a range of possible responses for its consideration to address the recommendations. In some instances, suggested responses include amending the Act. However, reliance on legislative solutions alone has limitations so the authors also set out a range of non-legislative responses such as issuing (or revising) policies and other forms of guidance, developing training and education, implementing practice changes and adjusting system design.

While all issues and relevant recommendations should be carefully considered, the authors identify three issues that should be addressed as a matter of priority ('priority issues'). These priority issues, along with the relevant recommendations needed to address them, are set out below:

## 1. Lack of public knowledge about the VAD system and difficulties associated with connecting to the system

- Improve community knowledge that VAD is a legal end-of-life option (Recommendation 1)
- Improve health practitioner knowledge of VAD, especially of medical practitioners, and educate these practitioners about their existing legal obligations when they receive a first request for VAD (Recommendations 2 and 4)
- Develop strategies to ensure medical practitioners provide information about VAD when requested by a patient (Recommendation 6).

## 2. Individuals and institutions, either intentionally or otherwise, impeding a patient's ability to access VAD

- Develop strategies to ensure medical practitioners provide information about VAD when requested by a patient (Recommendation 6)
- Impose obligations on all entities providing health, aged, residential and other care to facilitate access to VAD (Recommendation 8).



### 3. Limited VAD workforce to meet current demands and concerns for the current workforce's sustainability

- Develop strategies and explore opportunities to increase the VAD workforce (Recommendation 19)<sup>3</sup>
- Review current VAD practices and workload of existing VAD workforce (including VAD providers and those who have a role in VAD such as statewide services and VAD Coordinators) to ensure they are appropriately remunerated and supported (Recommendation 21).

Notwithstanding the priority issues (and relevant recommendations) identified above, the participants raised many issues for consideration. The authors have grouped the issues raised into six key themes, each of which is described in a separate chapter of this Report.

**Chapter 1** considers the awareness of VAD across the community and the health professions. It provides an overview of perceptions about the current levels of awareness of VAD, offers reflections on the efficacy of current strategies in place to raise awareness, and reflects on barriers to awareness of VAD.

**Chapter 2** is concerned with accessing and navigating the VAD system. It considers the range of barriers that affect a person's ability to connect with the VAD system, and navigate it once connected to it. These barriers include the current restrictions placed on health care workers with respect to raising VAD with patients, the first request process, conscientious and institutional objection, telehealth restrictions and patient-focused resources.

**Chapter 3** explores the application of VAD eligibility criteria. It offers general reflections on current eligibility criteria, as well as specific reflections on individual criteria and the difficulties that arise in practice. It also briefly considers issues associated with the mandatory waiting period.

**Chapter 4** explores the prescription, administration, transportation and disposal of the VAD substance and some of the challenges the VAD workforce, patients and their loved ones encounter in relation to such processes. It offers reflections on issues that can arise following a VAD death including the role of the contact person, grief and bereavement needs, and death certification.

**Chapter 5** considers the VAD workforce ranging from VAD practitioners, statewide services, institutional VAD supports, and the VAD Board and Secretariat. It considers the nature of the current workforce and its resourcing. It also outlines what is needed to ensure that the workforce is adequately supported, and the system is sustainable.

**Chapter 6** explores the design of the VAD system. It considers the structure and operation of the statewide services, issues arising with current restrictions on information-sharing and privacy constraints, reflections on the VAD Information Management System (VAD-IMS) and mandatory forms, considerations with respect to managing VAD within a health service, VAD's relationship with palliative care and the structural arrangement between the Department of Health, VAD Board and VAD Board Secretariat.

Within each chapter the authors have made several recommendations in response to the issues raised and have categorised them according to priority. These recommendations have been broadly categorised (and colour-coded) across three groups: (1) Recommendations that address the three 'priority issues' identified above and so should be implemented as soon as possible (**red**), (2) Recommendations that should be implemented as a next level priority as soon as possible (**orange**), and (3) Recommendations for consideration in future reviews (**green**).

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3 The authors acknowledge that the Department of Health has recently announced that it will be implementing a fee-for-service remuneration model for VAD practitioners which will see funding provided by the Department of Health over the 2024-25 and 2025-26 financial years to support VAD practitioners in non-salaried roles to claim payment for their clinical and administrative time. This initiative will take effect from 1 July 2024. However, it is noted that this is only a temporary solution, and the introduction of dedicated Medicare Benefit Schedule item numbers are the preferred longer-term solution for remuneration across Australia. See WA VAD Board, *Quality Practice Series #8* (Western Australian Government: Department of Health, May 2024) <<https://www.enudge.com.au/email-share-link.php?ca=llQd3fP9Q2sVSvNMK1OnkQ%3D%3D&cl=PzzsvLE3SKY9iDbfoMJRoQ%3D%3D>> (*Quality Practice Series #8*).

**Table 1: Authors' recommendations**

Recommendations that address the three priority issues that should be implemented as soon as possible	Recommendations that should be implemented as a next level of priority as soon as possible	Recommendations for consideration in future reviews
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Theme	Sub-theme	Recommendation
<b>Awareness of VAD</b>	Community awareness	1 Develop and implement a public communication and engagement strategy to increase public awareness of VAD.
	Health practitioner awareness	2 Develop and implement a strategy to increase health practitioners' awareness of VAD and their obligations.
<b>Accessing and navigating the VAD system</b>	Limits on raising VAD	3 Consider appropriate legislative and policy changes and education strategies to ensure health care workers can best navigate conversations about VAD, including raising VAD (where appropriate and permissible) with patients.
	First request	4 Through training and education, improve medical practitioner awareness of the first request process and how to respond appropriately.
		5 Improve system design so that a patient who makes a first request is connected with the VAD system.
	Individual conscientious objection	6 Develop strategies to ensure medical practitioners provide Approved Information about VAD to a patient who asks for information about VAD (and not just in cases of a first request).
		7 Develop strategies to ensure medical practitioners provide, as soon as practicable, clinical information about the patient or access to the patient's medical records (with the patient's consent) to a medical practitioner assessing their eligibility for VAD.
	Institutional objection	8 Impose obligations on all entities providing health, aged, residential and other care to facilitate access to VAD.
	Patient-focused resources	9 Review and revise the content, format and accessibility of consumer VAD resources.
<b>Eligibility assessment</b>	10	Future reviews of the WA VAD Act should consider current eligibility criteria for VAD.

Theme	Sub-theme		Recommendation
<b>Prescription, administration and disposal and post-death</b>	Prescription delivery	11	Broaden the category of individuals who are authorised to deliver a prescription to an authorised supplier.
	Transporting substance	12	When a patient transitions between care settings, facilitate the transport of the VAD substance to the new care setting by another person authorised by the patient to do so.
	Administration	13	Allow assistance to be provided to the patient, if requested, to prepare their VAD substance.
		14	Simplify the process for changing the method of administration including in cases where self-administration is no longer appropriate.
		15	Simplify the process of transferring the role of administering practitioner.
		16	Future reviews should consider amending legislation to permit practitioner administration if self-administration 'fails'.
	Storage and disposal	17	Make changes to legislation, forms, and/or current guidance to: <ul style="list-style-type: none"> <li>• establish or advise on a specific timeframe for the authorised disposal to occur; and</li> <li>• permit the administering practitioner to possess and dispose of the VAD substance to accommodate all cases where the practitioner is appropriately in possession of the substance.</li> </ul>
	Grief and bereavement	18	Review existing grief and bereavement supports currently available to assess suitability and availability to support individuals affected by a VAD death.

Theme	Sub-theme		Recommendation
VAD workforce	Expand the VAD workforce including in regional areas	19	<p>Develop strategies and explore opportunities to increase the VAD workforce including:</p> <ul style="list-style-type: none"> <li>adequate workload recognition or remuneration for medical practitioners providing VAD; and</li> <li>payment to complete the mandatory VAD training.</li> </ul>
		20	<p>Future reviews of the WA VAD Act should explore the feasibility of expanding the roles of other health practitioners in relation to VAD such as:</p> <ul style="list-style-type: none"> <li>nurse practitioners to assess eligibility; and</li> <li>senior nurses to act as administering practitioners.</li> </ul>
	Supporting and sustaining the VAD workforce	21	<p>Review current VAD practices and workload of existing VAD workforce (including VAD providers and those who have a role in VAD such as statewide services and VAD Coordinators) to ensure:</p> <ul style="list-style-type: none"> <li>participating practitioners are provided with adequate workload recognition or remuneration for providing VAD;</li> <li>statewide services are resourced sufficiently to provide required services including statewide travel and grief and bereavement support to family and carers; and</li> <li>access of the VAD workforce to services to support their self-care and wellbeing.</li> </ul>

Theme	Sub-theme		Recommendation
<b>VAD system design</b>	Structure and location of the statewide services	22	<p>Future reviews should consider whether the current structure, processes and resources of the statewide services are optimal for service delivery, including:</p> <ul style="list-style-type: none"> <li>• whether greater integration of statewide services is desirable;</li> <li>• whether Statewide Care Navigators should be located in regions with high VAD activity;</li> <li>• whether regional hubs should be established to dispense medication; and</li> <li>• whether out of hours support should be provided by the statewide services.</li> </ul>
	Information-sharing and privacy constraints	23	<p>Consider strategies such as legislative amendment or modification of system design to permit individuals who are fulfilling a role under the Act to have access to the information needed to undertake that role. This would include:</p> <ul style="list-style-type: none"> <li>• access to clinical information and medical records (which may include information about VAD) needed to assess eligibility or support a patient's VAD process; and</li> <li>• access (including for the Statewide Care Navigator Service [SWCNS], VAD Coordinators and nurse practitioners acting as administering practitioners) to the VAD Information Management System [VAD-IMS] as needed to support a patient's VAD application.</li> </ul>
		24	<p>Consider changes needed to legislation and/or practice to ensure the WA VAD Board can use information it receives to effectively and efficiently carry out its functions.</p>
	Structure and interaction between the Department, Board and Secretariat	25	<p>Future reviews should consider the optimal VAD oversight structure, including that which supports the VAD Board to operate independently and carry out its functions.</p>

# Background

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Western Australia (WA) was the second Australian jurisdiction to pass and introduce VAD laws.<sup>4</sup> The *Voluntary Assisted Dying Act 2019* (WA) ('WA VAD Act') came into force on 1 July 2021. The passing of the law was preceded by a Joint Select Committee Inquiry into End-of-Life Choices. The Committee made recommendations about advance care planning, palliative care and the implementation of VAD in its Final Report, *My Life, My Choice*,<sup>5</sup> released in August 2018. The WA Government then established a Ministerial Expert Panel to undertake consultation and develop legislation.<sup>6</sup> The Ministerial Expert Panel's Final Report was tabled on 27 June 2019. That Report informed the drafting of the Voluntary Assisted Dying Bill 2019. The Bill was introduced into Parliament in August 2019, and subsequently passed in December 2019. The WA VAD Act commenced operation following an 18-month implementation period.

## Authors' process

The authors were responsible for Stage Two of the Review which involved conducting semi-structured interviews and focus groups amongst key stakeholders (identified by the Panel) to further explore some of the themes and issues identified from Stage One. The authors contacted the identified key stakeholders to participate in a semi-structured interview or focus group.<sup>7</sup> Stakeholders included representation from VAD health practitioners who are currently involved in provision (including medical practitioners and a nurse practitioner), VAD Statewide Care Navigator Service (SWCNS), VAD Statewide Pharmacy Service (SWPS), VAD Advocacy Groups, health service providers' VAD Coordinators, VAD Board, VAD Board Secretariat, End of Life Care Program Team at the Department of Health (DoH) and family caregivers who supported a person through the VAD process. Not all stakeholders identified by the Panel agreed to participate or responded to the authors' invitations to participate.<sup>8</sup> The authors made several attempts to recruit health practitioners who were no longer involved in VAD provision (using contact details provided by the DoH); however, that recruitment was unsuccessful.

Ethics approval was obtained by QUT's University Human Research Ethics Committee [ID 20000002700]. Interview and focus group guides were developed by the authors and tailored to reflect the intended stakeholder group. Themes explored in the guides were informed by the researchers' knowledge of VAD, previous research, and themes identified from a preliminary analysis of Stage One data (based on a draft report supplied by the DoH to the authors).<sup>9</sup> Each guide sought specific feedback on: accessing the VAD system, assessment stages and application of eligibility criteria, dispensing, administration and disposal of the VAD substance, and post death supports and bereavement. The guides also offered an opportunity for participants to reflect on the WA VAD system as a whole. The Panel reviewed the interview and focus group guides and approved their use.

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4 Victoria was the first state with its *Voluntary Assisted Dying Act 2017* (Vic) which commenced operation in June 2019. See CM Haining, L Willmott and BP White, "Comparing Voluntary Assisted Dying Laws in Victoria and Western Australia: Western Australian Stakeholders' Perspectives" (2023) 30(3) *Journal of Law and Medicine* 714.

5 Joint Select Committee on End of Life Choices, *My Life, My Choice Report* (Western Australian Government, 2018) <[https://www.parliament.wa.gov.au/parliament/commit.nsf/\(Report+Lookup+by+Com+ID\)/71C9AFEC0FAEE6E482582F200037B37/\\$file/Joint+Select+Committe+on+the+End+of+Life+Choices+-+Report+for+Website.pdf](https://www.parliament.wa.gov.au/parliament/commit.nsf/(Report+Lookup+by+Com+ID)/71C9AFEC0FAEE6E482582F200037B37/$file/Joint+Select+Committe+on+the+End+of+Life+Choices+-+Report+for+Website.pdf)>.

6 Department of Health, *Ministerial Expert Panel on Voluntary Assisted Dying: Final Report* (Western Australian Government, 2019) <<https://www.health.wa.gov.au/-/media/Files/Corporate/general-documents/Voluntary-assisted-dying/PDF/voluntary-assisted-dying-final-report.pdf>>.

7 The authors were provided with desired participant categories and a list of contact details of specific individuals within each stakeholder group that the Panel wanted contacted.

8 The authors supplemented the Panel's original list to account for declined invitations and non-responders. To do this, the authors drew on an additional list provided by the DoH which contained contact details of personnel who participated in Stage One of the consultation process.

9 The authors were provided with an early analysis of the Stage One data by the DoH in January 2024: Department of Health, *Voluntary Assisted Dying Act 2019 Review – Stage 1: Early Draft Results* (Western Australian Government, January 2024).

A total of eight semi-structured interviews/focus groups (comprising between 2-7 participants) were carried out explicitly for this Review and took place via Zoom between October 2023-April 2024. Semi-structured interviews and focus groups were conducted by all three researchers, with one researcher taking the lead for each. For the purposes of analysis, the authors also drew on previous qualitative interview data from research carried out in WA, in 2022, by the same researchers.<sup>10</sup> This supplemental data captured perspectives from family caregivers, and aged care and palliative care organisations (including those not supportive of VAD) (n = 5). Only data from previous participants who were members of the stakeholder groups above, and who had provided extended consent to have their data used to inform the Review, were re-analysed for the purposes of this Report. Demographics of all participants whose data was analysed for the purpose of this Report have been recorded in Table 2.

**Table 2: Participant Demographics (n=38)**

<b>Total sample (n=38)</b>		
<b>Participant type</b>	Health practitioners	6
	Family caregivers	6
	Other	26
<b>Gender identity</b>	Female	27
	Male	11
<b>Age</b>	30-39	5
	40-49	9
	50-59	10
	60-69	7
	70+	7
<b>Location</b>	Metropolitan	35
	Regional	3
<b>Health practitioner characteristics (n=6)</b>		
<b>Number of cases</b>	<20	2
	20-50	1
	50-100	1
	100+	2
<b>Regional experience (including RASS)</b>		4
<b>Patient demographics (n=5)<sup>11</sup></b>		
<b>Gender</b>	Female	1
	Male	4
<b>Age at death</b>	60-69	2
	70-79	2
	80+	1
<b>Primary diagnosis</b>	Cancer	4
	Other	1
<b>Death</b>	Death from the VAD substance	4
	Non-VAD death	1

10 For further details on the study's methodology see Haining, Willmott and White, n 4, 730-732; CM Haining, L Willmott and BP White, "Accessing Voluntary Assisted Dying in Regional Western Australia: Early Reflections from Key Stakeholders" (2023) 23(4) *Rural and Remote Health* 8024.

11 No patients were included in the sample. However, six family caregivers who took part in this study were able to reflect on the experiences of five patients; two participants reflected on the same patient. One family caregiver's loved one was unable to complete the process.

Field notes were completed following each interview and focus group. Interviews and focus groups were transcribed by a professional transcription company. Transcripts were de-identified and sent to each participant who was provided with the opportunity to review and edit their data. Participants were also invited to provide the researchers with any supplementary documentation or send through additional thoughts they wanted to be included in the analysis. Data were imported into NVivo 14 and analysed using Braun and Clarke's approach to thematic analysis.<sup>12</sup> Data familiarisation occurred by relistening to each interview and focus group, and reading through each transcript in full multiple times. This process informed a coding framework which was reviewed, revised and agreed upon by all authors based on their recollection of the data and previous VAD research. The coded data was then organised into themes, which were reviewed and refined by all the authors, and have been reported on in this Report.

## Limitations

As is the case for all empirical research, this research has limitations. Firstly, the sample comprises a range of key stakeholders, but is ultimately small. While the sample contains representation from a variety of stakeholder groups, it does not include representation from patients undergoing the process, conscientious objectors, or VAD-trained practitioners who are no longer providing. Additionally, participants were contacted based on lists of desired participants determined by the Panel and DoH and, therefore, may not be representative of their respective groups, particularly amongst larger stakeholder groups such as health practitioners.

The limited sample means that some specific issues with the WA VAD Act may not have been raised and, therefore, are not addressed in this Report. This is because only issues explicitly referred to during the focus groups and interviews were included within the analysis. The authors note other specific issues (such as the wording in the WA VAD Act in relation to interpreters, the challenge of finding eligible witnesses for the purposes of the written declaration, and difficulties of intravenous (IV) access in relation to practitioner administration) have been raised publicly elsewhere.<sup>13</sup> Because these matters have been identified elsewhere and were not discussed by participants during interviews/focus groups, they have not been considered in this Report. Nevertheless, the authors consider that the methodology adopted for this research will have identified the broad range of issues with the WA VAD Act's operation and effectiveness.

There are also limitations inherent in the study design. For example, the interview and focus group guides used were necessarily broad to capture a range of themes. Therefore, some of the minutia and intricacies of the WA VAD system may not have been captured or directly probed. Similarly, there is potential that participants' responses may have been affected by the group dynamic. For example, participants may have been more careful in their responses (particularly with respect to sensitive information) than if they had participated in a one-on-one semi-structured interview.<sup>14</sup>

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12 V Braun and V Clarke, "Using Thematic Analysis in Psychology" (2006) 3(2) *Qualitative Research in Psychology* 77.

13 For reflections on issues relating to the WA VAD Act with respect to interpreters see Voluntary Assisted Dying Board Western Australia, Annual Report 2021-22 (2022) <<https://www.health.wa.gov.au/-/media/Corp/Documents/Health-for/Voluntary-assisted-dying/VAD-Board-Annual-Report-2021-22.pdf>> (WA VADB 2021-2022 Report) 39. For reflections on the difficulty in finding witnesses see Go Gentle Australia, "Stephen had a Peaceful Death", 13 December 2022 <[https://www.gogentleaustralia.org.au/stephens\\_voluntary\\_assisted\\_dying\\_experience](https://www.gogentleaustralia.org.au/stephens_voluntary_assisted_dying_experience)>; South Metropolitan Health Service, *This is My Stop: Lisa's Story* (Government of Western Australia) <<https://smhs.health.wa.gov.au/Our-community/Engaging-with-our-community/Navigating-and-understanding-the-voluntary-assisted-dying-experience>> (*This is My Stop: Lisa's Story*). For reflections on the difficulties with IV access see Voluntary Assisted Dying Board Western Australia, Annual Report 2022-23 (2023) <<https://www.health.wa.gov.au/-/media/Corp/Documents/Health-for/Voluntary-assisted-dying/VAD-Board-Annual-Report-2022-23.pdf>> (WA VADB 2022-2023 Report) 56.

14 JA Hollander, "The Social Context of Focus Groups" (2004) 33(5) *Journal of Contemporary Ethnography* 602.



## Key findings

Data analysis revealed that, apart from some notable issues, the WA VAD system is working well, once a patient is connected to the system. The WA VAD Act has provided an additional end-of-life choice for eligible Western Australians. The success of the WA VAD system has largely been attributed to the VAD workforce, including the statewide services and VAD Coordinators, who have been widely praised for their compassion and dedication to delivering person-centred care. Similar positive sentiments about the WA VAD system have been expressed elsewhere.<sup>15</sup> Data analysis resulted in the identification of six main themes: awareness of VAD; accessing and navigating the VAD system; eligibility assessment; prescription, administration, disposal and post-death; VAD workforce; and VAD system design. Each theme is considered in a separate chapter of this Report.

In each chapter, the authors have described the data relevant to the theme, evaluated the available evidence (participants' views and additional relevant evidence),<sup>16</sup> identified relevant issues and potential responses to address such issues. Where appropriate, the authors have also formulated recommendations. In total, the authors independently formulated 25 recommendations.<sup>17</sup> These recommendations have been broadly categorised (and colour-coded) across three groups: (1) Recommendations that address the three 'priority issues' identified below and so should be implemented as soon as possible (**red**), (2) Recommendations that should be implemented as a next level priority as soon as possible (**orange**), and (3) Recommendations for consideration in future reviews (**green**).

For the sake of completeness, this Report considers all significant issues raised by participants. While not all issues resulted in a response by way of recommendation, the authors encourage the DoH to monitor all the issues identified and consider whether a response may be needed now or in the future.

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15 S Blackwell, "Voluntary Assisted Dying in WA: The People's Choice" (2022) 62(1) *Medicus* 32; Haining, Willmott and White, n 4; Haining, Willmott and White, n 10; S Towler, "It Has Been a Privilege to Have Alleviated Significant Suffering ..." 62(1) *Medicus* 33; *WA VADB 2021-2022 Report*, n 13; *WA VADB 2022-2023 Report*, n 13; K Bourke, "WA's Voluntary Assisted Dying Laws Have Been in Place for a Year. Have they Served their Purpose?", *ABC News*, 1 July 2022 <<https://www.abc.net.au/news/2022-07-01/doctors-reflect-on-wa-voluntary-assisted-dying-scheme-a-year-on/101194566>>; D Colgan, "I Have Terminal Cancer. But Planning My Death Gives Me 'Calm And Euphoria'", *SBS News*, 4 July 2023 <<https://www.sbs.com.au/news/insight/article/i-have-terminal-cancer-but-planning-my-death-helps-me-to-live-better/84ki4svsd>>; C Elton, "Voluntary Assisted Dying Demand Three Times Greater than Expected, VAD Board Reveals", *The West Australian*, 10 February 2022 <<https://thewest.com.au/business/health/voluntary-assisted-dying-demand-three-times-greater-than-expected-vad-board-reveals--c-5642082>>; Go Gentle Australia, "Eternally Thankful", 30 July 2021 <[https://www.gogentleaustralia.org.au/aboriginal\\_woman\\_among\\_first\\_to\\_use\\_assisted\\_dying\\_law\\_wa](https://www.gogentleaustralia.org.au/aboriginal_woman_among_first_to_use_assisted_dying_law_wa)>; Go Gentle Australia, "Stephen had a Peaceful Death", n 13; Go Gentle Australia, "There Could Not be a Truer Love", 17 April 2023 <[https://www.gogentleaustralia.org.au/assisted\\_dying\\_there\\_could\\_not\\_be\\_a\\_truer\\_love](https://www.gogentleaustralia.org.au/assisted_dying_there_could_not_be_a_truer_love)>; Go Gentle Australia, "'We've Seen Gentle, Beautiful Deaths'", 22 November 2022 <[https://www.gogentleaustralia.org.au/fiona\\_jane\\_vad\\_hospice\\_experience](https://www.gogentleaustralia.org.au/fiona_jane_vad_hospice_experience)>; R Hirini, "First Known Aboriginal Voluntary Assisted Dying (VAD) Patient Mary-Ellen Passmore Dies in Perth Hospital", *The West Australian*, 30 July 2021 <<https://thewest.com.au/news/health/first-known-aboriginal-voluntary-assisted-dying-vad-patient-mary-ellen-passmore-dies-in-perth-hospital-ng-b881946986z>>; P Lundie, "Slow Start for Voluntary Assisted Dying" *Western Independent*, 8 November 2021 <<https://westernindependent.com.au/2021/11/08/slow-start-for-voluntary-assisted-dying/>>; R Parish, "Voluntary Assisted Dying Doctor Bhawani O'Brien Says New Laws Allow Terminally Ill People to Pass 'Peacefully'", *The Nightly*, 2 June 2024 <<https://thenightly.com.au/politics/voluntary-assisted-dying-doctor-bhawani-obrien-says-new-laws-allow-terminally-ill-people-to-pass-peacefully-c-14874857>>; South Metropolitan Health Service, *This is My Stop: Barbara's Story* (Government of Western Australia) <<https://smhs.health.wa.gov.au/Our-community/Engaging-with-our-community/Navigating-and-understanding-the-voluntary-assisted-dying-experience>> (*This is My Stop: Barbara's Story*); South Metropolitan Health Service, *This is My Stop: Dan's Story* (Government of Western Australia) <<https://smhs.health.wa.gov.au/Our-community/Engaging-with-our-community/Navigating-and-understanding-the-voluntary-assisted-dying-experience>> (*This is My Stop: Dan's Story*); South Metropolitan Health Service, *This is My Stop: Dr Gareth* (Government of Western Australia) <<https://smhs.health.wa.gov.au/Our-community/Engaging-with-our-community/Navigating-and-understanding-the-voluntary-assisted-dying-experience>> (*This is My Stop: Dr Gareth*); South Metropolitan Health Service, *This is My Stop: Gina's Story* (Government of Western Australia) <<https://smhs.health.wa.gov.au/Our-community/Engaging-with-our-community/Navigating-and-understanding-the-voluntary-assisted-dying-experience>> (*This is My Stop: Gina's Story*); *This is My Stop: Lisa's Story*, n 13; South Metropolitan Health Service, *This is My Stop: Sam's Story* (Government of Western Australia) <<https://smhs.health.wa.gov.au/Our-community/Engaging-with-our-community/Navigating-and-understanding-the-voluntary-assisted-dying-experience>> (*This is My Stop: Sam's Story*).

16 Other relevant evidence includes relevant peer-reviewed literature, VAD Board Reports and media accounts of the WA VAD system.

17 The Panel and DoH were given the opportunity to comment on a draft of this Report including draft recommendations. This feedback was considered by the authors, however, this Research Report and all the recommendations contained within it were developed by the authors alone.

The authors' approach to developing recommendations has been to identify the problematic issue/s which need to be addressed. Having identified these issues, the authors then provide the Panel with a range of possible responses for its consideration. In some instances, the optimal solution will be to amend the WA VAD Act. Where this is the authors' view, this will be clearly stated. However, the authors recognise that reliance on legislative solutions alone has limitations. Amending the WA VAD Act depends on parliamentary consensus which may or may not be present, and law reform can take time. There may, therefore, be a need for non-legislative responses such as issuing (or revising) policies and other forms of guidance, developing training and education, implementing practice changes and adjusting system design. Such responses have the advantage of being able to be implemented more quickly. The range of possible responses identified by the authors may also be seen to work together. To illustrate, a change in policy may provide an immediate response to mitigate a known problem, pending future law reform.

Finally, while there are a range of issues canvassed and recommendations made in this Report, the authors have identified three priority issues affecting the operation and effectiveness of the WA VAD Act. These priority issues, along with the relevant recommendations needed to address them, are set out below:

### **1. Lack of public knowledge about the VAD system and difficulties associated with connecting to the system**

- Improve community knowledge that VAD is a legal end-of-life option (Recommendation 1)
- Improve health practitioner knowledge of VAD, especially of medical practitioners, and educate these practitioners about their existing legal obligations when they receive a first request for VAD (Recommendations 2 and 4)
- Develop strategies to ensure medical practitioners provide information about VAD when requested by a patient (Recommendation 6).

### **2. Individuals and institutions, either intentionally or otherwise, impeding a patient's ability to access VAD**

- Develop strategies to ensure medical practitioners provide information about VAD when requested by a patient (Recommendation 6)
- Impose obligations on all entities providing health, aged, residential and other care to facilitate access to VAD (Recommendation 8).

### **3. Limited VAD workforce to meet current demands and concerns for the current workforce's sustainability**

- Develop strategies and explore opportunities to increase the VAD workforce (Recommendation 19)<sup>18</sup>
- Review current VAD practices and workload of existing VAD workforce (including VAD providers and those who have a role in VAD such as statewide services and VAD coordinators) to ensure they are appropriately remunerated and supported (Recommendation 21).

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18 The authors acknowledge that the DoH has recently announced that it will be implementing a fee-for-service remuneration model for VAD practitioners which will see funding provided by the DoH over the 2024-25 and 2025-26 financial years to support VAD practitioners in non-salaried roles to claim payment for their clinical and administrative time. This initiative will take effect from 1 July 2024. However, it is noted that this is only a temporary solution, and the introduction of dedicated Medicare Benefit Schedule item numbers are the preferred longer-term solution for remuneration across Australia. See *Quality Practice Series #8*, n 3.

# Chapter 1: Awareness of VAD

VAD laws were passed in WA in 2019 and, since July 2021, VAD has been available as a lawful end-of-life choice. Victoria was the first state to pass VAD laws in 2017, and the remaining four states and the Australian Capital Territory passed legislation between 2021 and 2024.<sup>19</sup> The Northern Territory is actively considering introducing laws.<sup>20</sup> During this period of reform, there has been considerable national coverage of, and discussion about, VAD. This has been important because access to VAD ultimately relies on individuals knowing that it is a lawful end-of-life option. Indeed, the need to improve awareness of VAD amongst the community and health practitioners has been identified as one of the WA VAD Board's strategic objectives.<sup>21</sup> This chapter provides an overview of participants' perceptions about the current levels of awareness of VAD amongst the community and the health profession.

## 1.1 Community awareness

In order for the community to be able to access VAD, they need to be aware that it is a lawful end-of-life option available to them. Awareness may arise through a person's own channels or discussions with health practitioners. Community awareness can also occur through other avenues. For instance, VAD stories occasionally feature in mainstream media, and there have been efforts by the VAD Board and the SWCNS, as well as other groups (such as Dying with Dignity Western Australia) to host community forums and webinars to raise awareness.<sup>22</sup> However, given VAD is a relatively new end-of-life choice available to Western Australians, it is likely that there are significant knowledge gaps within the community.<sup>23</sup> Raising patients' awareness empowers them to connect with the system and access VAD. This is particularly important in cases where patients may not be able to access VAD via their usual care team.

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19 VAD laws are in effect in all Australian states: *Voluntary Assisted Dying Act 2017* (Vic), *End-of-Life Choices (Voluntary Assisted Dying) Act 2021* (Tas), *Voluntary Assisted Dying Act 2021* (Qld), *Voluntary Assisted Dying Act 2021* (SA) and *Voluntary Assisted Dying Act 2022* (NSW). In June 2024, the Australian Capital Territory passed its VAD law. The *Voluntary Assisted Dying Act 2024* (ACT) will come into effect on 3 November 2025.

20 An expert advisory panel has been set up in the Northern Territory to develop a framework for VAD. See Department of the Chief Minister and Cabinet, *Voluntary Assisted Dying* (Northern Territory Government, 2024) <<https://cmc.nt.gov.au/project-management-office/voluntary-assisted-dying>>.

21 The WA Voluntary Assisted Dying Board's Strategic Plan 2023 to 2026 outlines six strategic objectives. One objective is to "[c]ontribute to community/health practitioner awareness and understanding of voluntary assisted dying, relevant to person (sic), role and stage of life". See *WA VADB 2022-2023 Report*, n 13, 58.

22 For examples see Department of Health, *End of Life Care: Voluntary Assisted Dying*, (Government of Western Australia) <[https://www.healthywa.wa.gov.au/Articles/A\\_E/End-of-life-care](https://www.healthywa.wa.gov.au/Articles/A_E/End-of-life-care)>; Dying with Dignity Western Australia, *Workshops* <<https://www.dwdwa.org.au/workshops>>; *Quality Practice Series #8*, n 3; *WA VADB 2022-2023 Report*, n 13, 52; A Cox, "Voluntary Assisted Dying Board of WA Visits Geraldton to Ensure Community's Questions are Answered", *Geraldton Guardian*, 11 March 2024 <<https://www.geraldtonguardian.com.au/news/geraldton-guardian/voluntary-assisted-dying-board-of-wa-visits-geraldton-to-ensure-communities-questions-are-answered-c-13901837>>.

23 Lack of awareness of VAD has been reported across Australia see BP White, R Jeanneret and L Willmott, "Barriers to Connecting with the Voluntary Assisted Dying System in Victoria, Australia: A Qualitative Mixed Method Study" (2023) 26 *Health Expectations* 2695, 2700; Go Gentle Australia and VADANZ, *Conference Report: VAD CON 2023* (2023) <[https://assets.nationbuilder.com/gogentleaustralia/pages/2656/attachments/original/1701247321/VADCON23\\_Report\\_GGA\\_\\_VADANZ\\_FINAL.pdf?1701247321](https://assets.nationbuilder.com/gogentleaustralia/pages/2656/attachments/original/1701247321/VADCON23_Report_GGA__VADANZ_FINAL.pdf?1701247321)> (*Conference Report: VAD CON 2023*) 10; Go Gentle Australia, *National Voluntary Assisted Dying Survey 2023* (2024) <[https://assets.nationbuilder.com/gogentleaustralia/pages/3028/attachments/original/1718839575/GGA\\_NationalVADSurvey\\_Report\\_A4\\_DIGITAL.pdf?1718839575](https://assets.nationbuilder.com/gogentleaustralia/pages/3028/attachments/original/1718839575/GGA_NationalVADSurvey_Report_A4_DIGITAL.pdf?1718839575)> (*National VAD Survey*); Queensland Voluntary Assisted Dying Review Board, *Annual Report 2022- 2023* (2023) <<https://www.health.qld.gov.au/research-reports/reports/departamental/voluntary-assisted-dying-review-board-annual-report>> (*Queensland VADRB Annual Report 2022-2023*) 31; South Australian Voluntary Assisted Dying Board, *Voluntary Assisted Dying in South Australia: Quarterly Report 31 January to 30 April 2023* (2023) <<https://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/services/primary+and+specialised+services/voluntary+assisted+dying/reporting/voluntary+assisted+dying+reporting>> (*South Australia VADRB Quarterly Report 31 January to 30 April 2023*) 3; *This is My Stop: Dan's Story*, n 15; *This is My Stop: Gina's Story* n 15; *This is My Stop: Sam's Story* n 15; M Marozzi, "Guidelines Needed for Voluntary Assisted Dying Patients Regarding Organ Donation, Experts Say", *ABC Radio Melbourne*, 18 July 2023 <<https://www.abc.net.au/news/2023-07-18/organ-donor-guidelines-needed-voluntary-assisted-dying-patients/102609600>>.

## *Participants' submissions and evidence*

Participants acknowledged that in the absence of any studies or polling, it is difficult to gauge the level of community awareness of VAD in WA. There was a sense that knowledge had increased over time due to increasing national discussion and discourse about VAD, or through knowledge of someone who had been through the process. There have been accounts where patients and their families have been motivated to share their VAD story in the media to help raise awareness about VAD and help break down stigma.<sup>24</sup> Participants noted that any time VAD featured in the media (whether positively or negatively), this correlated with an increase in VAD enquiries.

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*It was only just the other day I was talking to someone about voluntary assisted dying and they said, "It's a pity I've got to go to Switzerland to access it". And I went, "Well hang on a minute, no we've had it in the state for nearly three years". [Participant 24]*

*We almost celebrate at the moment, even if it's negative press, [because] at least people are becoming more aware of VAD as an option. So, it's definitely an area that needs growth. [Participant 11]*

*I think there is increasing community awareness now that we're seeing people who are referring to – well, I know that my friend's aunt did VAD ... that just friend of a friend ... But at the same time, I think there is a lot of misinformation and just lack of information. [Participant 6]*

Despite this perception of an increasing level of awareness, overall community knowledge of VAD, like knowledge of end-of-life and death literacy more generally, was believed to be patchy across the state. Participants indicated that there were still people in the community who were unaware that VAD is available. Levels of awareness also appeared to vary regionally.

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*We definitely see differences in the regions. Death literacy and awareness around end-of-life options is really different across each individual region of WA, and even subsets within that region. If I think about our Great Southern there's a really different understanding about what end-of-life care could look like in Kalgoorlie than there is in Esperance. Things are really, really different ... depending on their cultural awareness and understanding. I think we are still a long way from there being broad community understanding that VAD is an available option. [Participant 3]*

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<sup>24</sup> Hirini, n 15; Go Gentle Australia, "Stephen had a Peaceful Death", n 13. See also R Jeanneret et al, "'Regulatory Action' by Patients and Family Caregivers to Overcoming Barriers to Accessing Voluntary Assisted Dying: A Qualitative Study in Victoria, Australia" [2024] 47(3) *University of New South Wales Law Journal* (forthcoming).

Participants identified that people were more likely to be aware of VAD if they knew of someone who went through the process, or if a health practitioner raised VAD with them. In WA, medical practitioners and nurse practitioners are able to raise the topic of VAD with patients, provided at the same time they also inform the person about palliative and treatment options available to the person, and the likely outcomes of that care and treatment.<sup>25</sup> This aspect of the law has been favoured over more restrictive approaches taken in other states where health practitioners are prohibited from raising VAD.<sup>26</sup> Indeed, the current prohibitions were perceived to constrain raising awareness about VAD and, as will be discussed subsequently, act as a barrier to connecting with the system (see 2.1).

Notably, however, while the ability of certain health practitioners to raise VAD was viewed favourably, this would only be effective when the particular health practitioner knew about VAD which, as will subsequently be discussed in 1.2, is not always the case. Participants observed that people living in regions with limited (or no) VAD providers were less likely to be aware of VAD.

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*[In] regional areas ... [I get] a lot of the feedback ... in particular areas [that] their doctors are very transient and often the GPs [General Practitioners] are only there for a short amount of time. They might be overseas doctors that come in and they're also not aware that this is legislation and not aware of what even to do. [There's] often ... this cultural religious influence there as well ... I definitely think our regional patients still ... struggle with access. [Participant 4]*

Moreover, participants perceived that those who frequently engaged with the healthcare system (e.g. those who regularly attended hospitals for treatment) were more likely to have contact with medical and nurse practitioners and hence tended to be more aware of VAD, compared to those who were predominately receiving community care. Indeed, those receiving community care were less likely to come into contact with medical practitioners and nurse practitioners compared to other health care workers such as registered nurses and social workers, who are currently prohibited from raising VAD.

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*I actually think there's probably greater awareness amongst the people that I see, who are presenting frequently to hospitals than possibly within the medical fraternity. [Participant 5]*

Participants observed that there were efforts to raise awareness of VAD, particularly when the law commenced operation. Participants acknowledged community visits by the VAD Board and others (e.g. SWCNS) with the goal of raising awareness. While such efforts have been praised, participants identified scope to do more, including ongoing public education. Previous research has identified the need for broad scale community education to raise awareness of VAD, particularly because widespread awareness of VAD does not exist given its recent introduction into the Australian healthcare system.<sup>27</sup>

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25 *Voluntary Assisted Dying Act 2019* (WA) s 10.

26 *Voluntary Assisted Dying Act 2017* (Vic) s 8; *Voluntary Assisted Dying Act 2021* (SA) s 12. For empirical evidence and commentary on the impacts of placing restrictions on raising VAD see B Moore, C Hempton and E Kendal, "Victoria's Voluntary Assisted Dying Act: Navigating the Section 8 Gag Clause" (2020) 212(2) *Medical Journal of Australia* 67; C Johnston and J Cameron, "Discussing Voluntary Assisted Dying" (2018) 26(2) *Journal of Law and Medicine* 454; Haining, Willmott and White, n 4, 733-4; J Rutherford, L Willmott and BP White, "What the Doctor Would Prescribe: Physician Experiences of Providing Voluntary Assisted Dying in Australia" (2021) 87(4) *OMEGA* 1063,1071-1072; BP White et al, "Access to Voluntary Assisted Dying in Victoria: A Qualitative Study of Family Caregivers' Perceptions of Barriers and Facilitators" (2023) 219(5) *Medical Journal of Australia* 211, 213-214; White, Jeanneret and Willmott, n 23, 2702-2703; L Willmott et al, "Participating Doctors' Perspectives on the Regulation of Voluntary Assisted Dying in Victoria: A Qualitative Study" (2021) 215(3) *Medical Journal of Australia* 125, 126-127; L Willmott et al, "Restricting Conversations about Voluntary Assisted Dying: Implications for Clinical Practice" (2020) 10(1) *BMJ Supportive and Palliative Care* 105; *Conference Report: VAD CON 2023*, n 23, 8; *National VAD Survey*, n 23; Victorian Voluntary Assisted Dying Review Board, *Report of Operations: July 2021-June 2022* (2022) <<https://www.safercare.vic.gov.au/reports-and-publications/voluntary-assisted-dying-report-of-operations-july-2021-to-june-2022>> (*Victorian VADRB Report July 2021-June 2022*) 30; Victorian Voluntary Assisted Dying Review Board, *Report of Operations: July 2022 -June 2023* (2023) <<https://www.safercare.vic.gov.au/reports-and-publications/voluntary-assisted-dying-review-board-annual-report-july-2022-to-june-2023>> (*Victorian VADRB Report July 2022- June 2023*) 2.

27 White, Jeanneret and Willmott, n 23, 2701.

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*There was a lot of community awareness ... leading up to the commencement of voluntary assisted dying, and when we look back at it now some of it's not really that good ... [the] websites and so on ... maybe one of the things out of this Review is to say, "Let's go out there and educate the public again, because it's now three years ... and it's time for a boost I think". [Participant 23]*

Participants also identified that while VAD resources are available, finding them often depended on the patient (or their loved ones) knowing VAD existed which, as discussed above, was not always the case. The fact that VAD was seldom mentioned in end-of-life resources more broadly was believed to contribute to this lack of awareness.<sup>28</sup>

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*In terms of community awareness, another issue that I certainly struggle with and have heard from our patients on a number of occasions, is that there's no information about VAD available in other end-of-life care documents. Which is really, really challenging. Patients say they go to an appointment, they're sitting in a waiting room, or they have contact with a specialist service or care provider, they get information on absolutely everything, but VAD is not there. If they didn't know that it was available before, they're certainly not going to find any reference to it with[in] all of the other resources. Which is really overwhelming and challenging when you think you're being given everything that's available and there's a clear absence. [Participant 5]*

### *Issue identified*

VAD is still a relatively new end-of-life option. There is a need for broad scale initiatives to help raise public awareness of VAD.

### *Recommended responses*

A public communication and engagement strategy to increase community awareness of VAD should be developed and implemented. The authors recognise that the Access Standard addresses the issue of "access to information about voluntary assisted dying" and raise for consideration whether the authors' proposed strategy should be formally included within the Standard.<sup>29</sup>

Any awareness-raising initiative introduced should appropriately engage diverse populations including those who may have lower levels of health literacy. Initiatives should also be culturally appropriate and informed by consultation with relevant groups. The strategy, and any associated initiatives, should acknowledge the important role of health practitioners in raising community awareness and the need to improve existing resources. The authors have made a specific recommendation about patient-focused resources later in this Report (see Recommendation 9).

## **Recommendation 1**

**Develop and implement a public communication and engagement strategy to increase public awareness of VAD.**

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<sup>28</sup> The lack of information about VAD in general end-of-life care resources has previously been observed see *This is My Stop: Lisa's Story*, n 13.

<sup>29</sup> The Access Standard is issued by the CEO of the DoH pursuant to section 156 of the *Voluntary Assisted Dying Act 2019* (WA). The Access Standard sets out the ways in which WA intends to facilitate access to "(a) the services of medical practitioners and other persons who carry out functions under the Act, (b) prescribed substances and (c) information about accessing VAD". It also sets out the series of initiatives dedicated to facilitating regional access. While the Access Standard does include initiatives dedicated to facilitating access to information VAD, it does not include provision for broad scale community awareness. See Department of Health, *Voluntary Assisted Dying Act 2019 Access Standard* (Government of Western Australia, 2020) <<https://www.health.wa.gov.au/-/media/Corp/Documents/Health-for/Voluntary-assisted-dying/Access-Standard.pdf>> (*Access Standard*) 2.



## 1.2 Health practitioner awareness

Regardless of whether a health practitioner is able (or willing) to actively participate in the VAD process, it is important that they have some understanding of the VAD system given it is now an end-of-life option for eligible Western Australians. This level of understanding is important because the WA VAD Act prescribes a series of obligations, and sets out a series of offences, which are relevant to all health practitioners regardless of whether they are accredited VAD practitioners. Patients also depend on health practitioners for accessing health information. Hence, it is important that health practitioners have sufficient knowledge of VAD so they can pass on appropriate information to patients and raise it as a potential end-of-life option with them where appropriate (and when they are comfortable doing so).

### *Participants' submissions and evidence*

Participants reported that awareness of VAD amongst health professions was generally poor, with many health practitioners either unaware that VAD is a lawful end-of-life option or knew very little about the process other than that it was lawful.<sup>30</sup> This lack of understanding, particularly amongst the medical profession, meant health practitioners were unaware of their legal obligations under the WA VAD Act, particularly in response to the first request process (discussed later in 2.2).



*I think of concern is still the lack of awareness amongst some of the medical fraternity in particular. Who some of them still don't even know it's law, let alone what their obligations are. We've certainly had patients and families raise it with doctors. [Participant 5]*

*Doctors probably know that it's there, but they choose not to become very familiar with it unless it gets close enough to them that they sort of have to. [Participant 23]*

Another common area of uncertainty amongst health practitioners related to whether they were able to raise VAD or engage in conversations about VAD with patients.



*I've just had two cases in the last week where the consultants have said, "It's just such a shame that we couldn't raise this with the patient". Then I've said, "Well actually you can, that our legislation allows for that" ... There's a lot of stuff that, even in people who are happy to refer their patients, they're not aware of what they can and can't say sometimes, which is a challenge ... especially considering that it's going to be three years in July since the legislation was enacted. [Participant 7]*

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<sup>30</sup> Lack of general awareness of VAD amongst health practitioners and the need to improve knowledge have been reported elsewhere see CJ McLaren and G Mewett, "Update on Voluntary Assisted Dying in Australia" (2021) 215(3) *Medical Journal of Australia* 115; J Rutherford, "Doctors and the Voluntary Assisted Dying Act 2017 (Vic): Knowledge and General Perspectives" (2020) 27 *Journal of Law and Medicine* 952; White, Jeanneret and Willmott, n 23, 2700; *Conference Report: VAD CON 2023*, n 23, 7; Parish, n 15.

Participants acknowledged that there had been efforts to educate health professions including through community forums, webinars and resources produced by the DoH, the VAD Board (e.g. Quality Practice Series) and by various workplaces.<sup>31</sup> While participants identified that there are range of VAD resources available, there was a sense that there was a lack of buy-in or that the resources were not necessarily well-targeted or apt for health practitioners who were unaware of the process.

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*There are all these little bits of good quality information out there, but we don't know what's mandatory, how often it's accessed, who is actually using it and if it's having the intended effect that we would like it to have. [Participant 18]*

*The Guidelines are a fantastic resource, but the people that we're dealing with haven't read the Guidelines. Or they've read the Guidelines very superficially because they've gone, "Someone's just asked me about voluntary assisted dying and I'm a baby doctor, what do I do?" [Participant 19]*

Participants expressed support for bite-sized information and shorter education modules. Additionally, participants identified the value of one-on-one training and mentorship for some of the more clinical aspects of the process.

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*I think given the length of time that the training takes, I'm fairly OK with people having shorter and more accessible general resources available to any practitioner, like around modules etc. and then people can go ... "this is an area of interest to me, and I'm going to go and commit the 8 hours or whatever it is to do the training". [Participant 19]*

*The Community of Practice is looking at trying to offer some more formalised mentorship ... I certainly don't think ... that the training to become credentialed needs to be changed because I do think it's a separate element. I think if you added too much more, it's already quite overwhelming. I think we're talking about that practical side ... The idea of that watch one, do one, teach one. [Participant 11]*

Participants also supported greater integration of VAD within existing medical curriculum including at a tertiary level (whether as part of the core curriculum or as a guest lecture) or in speciality training. The need for VAD to be covered in other health professions' curriculum such as nursing and pharmacy was also identified.

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*I think we can make some inroads there whether that be targeted education sessions through colleges ... Similarly to that as well, other jurisdictions are moving into education in the undergraduate degree for the medical space. But equally that should probably be a key theme for other applicable disciplines as well. Whether that [just] be [a] brief mention of what [the] roles and responsibilities are. [Participant 10]*

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<sup>31</sup> For information about VAD, including resources specifically targeted at health practitioners, see Department of Health, *Voluntary Assisted Dying* (Government of Western Australia) <[https://www.health.wa.gov.au/Articles/U\\_Z/Voluntary-assisted-dying](https://www.health.wa.gov.au/Articles/U_Z/Voluntary-assisted-dying)>. For the WA VAD Board's Quality Practice Series, see WA VAD Board, *Practitioner Quality Practice Series* <[https://www.health.wa.gov.au/Articles/U\\_Z/Voluntary-Assisted-Dying-Board](https://www.health.wa.gov.au/Articles/U_Z/Voluntary-Assisted-Dying-Board)>.



Significantly, participants noted that the development of resources or provision of information alone was unlikely to raise awareness. Multiple participants identified a need for an overarching strategy which set out various actions and supported ongoing education and reinforcement, and engagement with appropriate channels to ensure that it was filtering down to the workforce.

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*[T]here's a lot of education things that are out there, but the biggest thing [I] found in my experience in promotion and prevention was the repetition. [Education] had to be part of our core business and it always had to be repeated. [Participant 21]*

*I think the issue is that whilst ... [a] training module ... can sit on [a] website, if we don't have that sort of ability to be engaging with different organisations and feeding it out ... it's going to be less value. [Participant 19]*

### *Issues identified*

Many health practitioners currently have insufficient knowledge about VAD. Education of health practitioners is needed to promote compliance with legal and system requirements, and to help support access to VAD by ensuring patients are provided with correct information about VAD, where relevant.

### *Recommended responses*

The authors support the development of a strategy encompassing a range of initiatives that will help build health practitioner awareness of VAD and their obligations. Such initiatives should include consideration of how existing resources can be improved and identify gaps for additional resources. An example given by participants was a short online education module available to all practitioners.<sup>32</sup> Training initiatives should be appropriate for their target audience, acknowledging that different health practitioners will have varying levels of involvement in the VAD process due to the nature of their profession, qualifications and beliefs about VAD. Providing further opportunities for mentoring and in-person training might also be considered. Given the important role of health practitioners in responding to patient enquiries about VAD, the DoH may wish to consider including commitments to improve health practitioners' knowledge in the Access Standard.

## **Recommendation 2**

**Develop and implement a strategy to increase health practitioners' awareness of VAD and their obligations.**

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<sup>32</sup> In Queensland, such a form of training exists (education module for healthcare workers) see Queensland Health, *Voluntary Assisted Dying* <<https://www.health.qld.gov.au/clinical-practice/guidelines-procedures/voluntary-assisted-dying>>.

# Chapter 2: Accessing and navigating the VAD system

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The number of people accessing VAD in WA has exceeded initial estimates.<sup>33</sup> There is also evidence that a diverse cohort of people across a range of cultural backgrounds and various levels of education have been able to access VAD in WA.<sup>34</sup> The Access Standard (and the initiatives it provides for) and other strategies have been implemented to provide access to this choice, particularly with respect to regional access.<sup>35</sup> Despite this, a number of barriers were found to affect the ability of a person to access VAD such as the limits on raising VAD, the current first request process, individual conscientious objection, institutional objection, telehealth restrictions and current patient-focused resources. These barriers can affect the ability of a person to connect to the VAD system and navigate the system once they are connected to it.

## 2.1 Limits on raising VAD

Section 10 of the WA VAD Act permits medical and nurse practitioners to initiate a discussion about or suggest VAD to a patient provided, at the same time, the practitioner informs the patient about other treatment and palliative care options, and the likely outcomes of such care and treatment.<sup>36</sup> Any other health care worker (registered health practitioner or person who provides health or professional care services to the patient)<sup>37</sup> is prohibited from raising (or suggesting) VAD, although they can engage in a discussion or provide information about VAD at the patient's request.<sup>38</sup> Restricting a health care worker's ability to discuss VAD with patients has the potential to create access barriers.<sup>39</sup>

### *Participants' submissions and evidence*

Participants considered that the ability of medical (and nurse) practitioners to raise VAD with patients played a significant role in building awareness and facilitating access. The WA approach is preferable to that taken in some other states (Victoria and South Australia) where health practitioners are prohibited from raising VAD with the patient, which has been found to create access challenges.<sup>40</sup>

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33 Blackwell, n 15; Haining, Willmott and White, n 4, 732-733; RW Hunt, "Voluntary Assisted Dying in Australia: Emerging Questions" (2023) 219(5) *Medical Journal of Australia* 208, 209; *WA VADB 2021-2022 Report*, n 13; Bourke, n 15; Elton, n 15; Lundie, n 15.

34 *WA VADB 2021-2022 Report*, n 13, 18-19; *WA VADB 2022-2023 Report*, n 13, 24-25; Bourke, n 15.

35 See *Access Standard*, n 29. For further discussion of the Access Standard particularly with respect to its role in facilitating regional access see Haining, Willmott and White, n 4; Haining, Willmott and White, n 10; L Willmott, CM Haining, BP White, "Facilitating Regional and Remote Access to Voluntary Assisted Dying in Western Australia: Targeted Initiatives During the Law-Making and Implementation Stages of Reform" (2023) 23(1) *Rural and Remote Health* 7522.

36 *Voluntary Assisted Dying Act 2019* (WA) s 10(2)-(3).

37 *Voluntary Assisted Dying Act 2019* (WA) s 10(1).

38 *Voluntary Assisted Dying Act 2019* (WA) ss 10(2),(4).

39 Haining, Willmott and White, n 4, 733-734; Johnston and Cameron, n 26; Moore, Hempton and Kendal, n 26; Rutherford, Willmott and White, n 26, 1071-1072; White et al, n 26, 213-214; White, Jeanneret and Willmott, n 23, 2702-2703; Willmott et al, "Restricting Conversations about Voluntary Assisted Dying: Implications for Clinical Practice", n 26; Willmott et al, *Participating Doctors' "Perspectives on the Regulation of Voluntary Assisted Dying in Victoria: A Qualitative Study"* n 26, 126-127; *Conference Report: VAD CON 2023*, n 23, 8.

40 *Voluntary Assisted Dying Act 2017* (Vic) s 8; *Voluntary Assisted Dying Act 2021* (SA) s 12. See also Haining, Willmott and White, n 4, 733-734.

However, the WA law governing how medical and nurse practitioners may discuss VAD has still been identified as problematic. One issue is that treating VAD differently from other end-of-life choices can constrain open discussions about these decisions and give rise to possible stigma.<sup>41</sup> Another concern stems from the complexity of the law. Section 10 of the WA VAD Act creates a blanket prohibition on all health care workers initiating a discussion about VAD or suggesting it, and then creates the above exception for medical and nurse practitioners provided certain information is given to the patient. The complexity of the current law, and limitations imposed on some health practitioners, has led to uncertainty about the extent to which health practitioners can lawfully engage in VAD conversations.<sup>42</sup> This has meant that some health practitioners have found it difficult to navigate VAD conversations in practice and, in some cases, has made them more anxious to engage in end-of-life discussions more broadly.<sup>43</sup>

Participants also considered that the prohibitions placed on other health care workers were unnecessarily restrictive and created access barriers. This is particularly so because patients often spend little time with medical and nurse practitioners compared to other care providers such as nurses (who are not nurse practitioners) and social workers. Participants expressed a desire to permit other care providers to raise VAD where appropriate.<sup>44</sup>

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*Doctors generally spend the smallest amount of time of all health professionals with a patient. Being wholly and solely sometimes dependent on a single provider to know what VAD is. To know that they're able to talk about it and then to feel comfortable raising it with a patient is a very small, very tiny window, considering the amount of time that senior nursing staff spend with patients, that social work spend with patients and sometimes that power imbalance that patients have with doctors about being comfortable raising it. There's a whole lot of factors there that impact an ability for a person to understand their options and also to have a frank and honest conversation about it to explore them. [Participant 3]*

*I think that the inability of particular health professional groups to raise voluntary assisted dying proactively with people, mean the type of people that are likely to be delivering ongoing care and having ongoing relationships with people towards end of life ... aren't able to be proactive. So, combine that lack of general knowledge and the inability to actually be given information in the context of a consultation or your care being provided by a non-medical practitioner or a nurse practitioner, I think that that is probably the big issue that we have there in terms of awareness and access. [Participant 19]*

### *Identified issues*

There is uncertainty and confusion within the health professions about whether VAD can be raised with patients, by whom, and subject to what limits. This means that some medical and nurse practitioners do not feel able to raise VAD, despite it being lawful to do so. Section 10 of the WA VAD Act also prohibits other health care workers from raising VAD which further adversely affects the ability of patients to know about VAD.

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41 White, Jeanneret and Willmott, n 23, 2702.

42 Such findings are consistent with what has been reported previously see Haining, Willmott and White, n 4, 734.

43 Previous research found that the current restrictions on raising VAD in WA has meant that some health practitioners (e.g. nurses) have expressed concerns about engaging in end-of-life discussions in case VAD is raised see Haining, Willmott and White, n 4, 734.

44 The desire to permit other health care workers to raise VAD with patients in WA has been reported elsewhere see Haining, Willmott and White, n 4, 734; F Carberry, "When Psychologists are Unable to Discuss Voluntary Assisted Dying, Patients Suffer", *Croakey*, 14 June 2023 <<https://www.croakey.org/when-psychologists-are-unable-to-discuss-voluntary-assisted-dying-patients-suffer/>>.

## Recommended responses

Allowing medical and nurse practitioners to raise VAD with patients is preferable to the position in some other states. However, section 10 of the WA VAD Act remains problematic. The authors consider the optimal approach to addressing this would be to amend the legislation to remove section 10. This would result in health practitioners being able to discuss VAD in the same way as all other end-of-life choices. Removing complexity in this aspect of the law and the resulting confusion for health practitioners will promote optimal conversations at the end of life.

A further benefit of removing section 10 is that it removes the distinction between medical and nurse practitioners and other health care workers. Participants identified that a range of health care workers, such as nurses and social workers, can be an appropriate source of information about VAD for patients, so it is important that they can have frank and open conversations about all available end-of-life options. Removing section 10 would not affect existing duties that health practitioners have in relation to informed consent, and the professional obligation to provide patients with all the necessary information they need to make informed decisions. Removing this section would also not affect duties health practitioners have to act within their scope of practice. Health practitioners should only raise VAD where this is appropriate and within their scope of practice and, if this occurs, they would also need to provide information about the spectrum of end-of-life options relevant to a patient, including palliative care.

Additional non-legislative strategies will help address the issues identified. Education of medical and nurse practitioners would support them to know that they can raise VAD with patients provided they do so in accordance with the law (which requires them to also raise other treatment and care options). A useful tool may be the recently developed 'Guiding Principles for Health Professionals' which suggest that "when the law permits this, health professionals *should* inform people about VAD if this could be an option for them" (emphasis added).<sup>45</sup> The creation of other resources such as conversation guides to help health practitioners navigate these conversations should also be considered.<sup>46</sup>

Health care workers who are not able to raise VAD with patients should also be made aware of lawful strategies to ensure their patients are aware of VAD where appropriate. This may include encouraging patients to ask their medical or nurse practitioner to discuss all end-of-life options with them or, where applicable, speaking with medical or nurse practitioners responsible for the patient's care to indicate that raising VAD with a particular patient may be appropriate.

## Recommendation 3

**Consider appropriate legislative and policy changes and education strategies to ensure health care workers can best navigate conversations about VAD, including raising VAD (where appropriate and permissible) with patients.**

45 See *Guiding Principles for Health Professionals – Voluntary Assisted Dying in Advance Care Planning Conversations*: Australian Centre for Health Law Research and Advance Care Planning Australia, *Navigating the Topic of Voluntary Assisted Dying in Advance Care Planning Conversations* (2024) <<https://www.advancecareplanning.org.au/about-us/available-support-materials>>.

46 For an example of conversation guides see Queensland Health, *Conversation Guides for GPs: Voluntary Assisted Dying* (Queensland Government, 2023) <[https://www.health.qld.gov.au/\\_\\_data/assets/pdf\\_file/0034/1195675/Conversation-guide-on-voluntary-assisted-dying-for-GPs.pdf](https://www.health.qld.gov.au/__data/assets/pdf_file/0034/1195675/Conversation-guide-on-voluntary-assisted-dying-for-GPs.pdf)>.

## 2.2 First request

Under the WA VAD Act, to begin the VAD process, a person must make a first request for VAD to a medical practitioner.<sup>47</sup> The request must be clear and unambiguous, and made during a medical consultation.<sup>48</sup> Merely seeking information or expressing curiosity about VAD is not considered to be a first request.<sup>49</sup> When a patient makes a first request to a medical practitioner, the medical practitioner must accept or refuse the patient's first request within two business days (or immediately in the case of conscientious objection).<sup>50</sup> A medical practitioner can refuse a patient's first request if they have a conscientious objection to VAD or is otherwise unwilling or unable (e.g. due to availability or inability to act as a coordinating practitioner).<sup>51</sup> A medical practitioner who may be eligible to be a coordinating practitioner but has not yet completed the training, may accept a first request. However, they cannot proceed to a first assessment until the training is completed.<sup>52</sup>

The medical practitioner is required to record the first request in the patient's medical record and whether it has been accepted or refused.<sup>53</sup> At that time, the medical practitioner must provide the patient with information approved by the CEO ('Approved Information').<sup>54</sup> The practitioner must also notify the VAD Board of the request within two business days, via the completion of the First Request Form which is submitted to the VAD Board Secretariat through the VAD-IMS (or fax).<sup>55</sup> Recording a first request serves the purpose of notifying the VAD Board of the outcome of a patient's first request. It does not generate a referral or pass on the patient's details to a VAD practitioner or the SWCNS.

### *Participants' submissions and evidence*

Issues with the first request process and connecting with the system were observed across all participant groups and have been identified previously including by the WA VAD Board in its Annual Report.<sup>56</sup> Indeed, the WA VAD Board noted that the first request process was an area that should be considered as part of this Review.<sup>57</sup>

Participants noted that many non-VAD practitioners were unaware of how the process worked and/or the nature of their obligations when they receive a first request from a patient. The current terminology used and the nature of the first request process was a significant source of confusion. Indeed, participants reported that many medical practitioners did not understand the difference between a first request and a request for information, and in the case of the former, that they are required to log the request on the VAD-IMS and provide the patient with the Approved Information. Similarly, participants noted that some medical practitioners were unaware that they had to both log a first request and provide a patient with the Approved Information regardless of whether they were a VAD practitioner (and registered with the VAD-IMS) and in a position to accept the first request.

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47 *Voluntary Assisted Dying Act 2019* (WA) s 18.

48 *Voluntary Assisted Dying Act 2019* (WA) s 18(2).

49 Department of Health, *Voluntary Assisted Dying Guidelines* (Western Australian Government, 2021) <<https://www.health.wa.gov.au/~/-/media/Corp/Documents/Health-for/Voluntary-assisted-dying/VAD-guidelines.pdf>> (*WA VAD Guidelines*) 29.

50 *Voluntary Assisted Dying Act 2019* (WA) ss 20(4)-(5).

51 *Voluntary Assisted Dying Act 2019* (WA) s 20(2).

52 *WA VAD Guidelines*, n 49, 30.

53 *Voluntary Assisted Dying Act 2019* (WA) s 21.

54 Department of Health, *Information about Voluntary Assisted Dying (VAD)* (Western Australian Government, 2024) <<https://www.health.wa.gov.au/~/-/media/Corp/Documents/Health-for/Voluntary-assisted-dying/Approved-information-booklet.pdf>>; *Voluntary Assisted Dying Act* (WA) ss 20(4)-(5).

55 *Voluntary Assisted Dying Act 2019* (WA) s 22; *WA VAD Guidelines*, n 49, 30.

56 *WA VADB 2022-2023 Report*, n 13, 55; For other examples of issues and poor understanding of the first request process in WA see Parish, n 15; *This is My Stop: Sam's Story*, n 15.

57 *WA VADB 2022-2023 Report*, n 13, 55.

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*People struggle with ... the first request. This is very confusing for clinicians because there's the first request which most of them have to decline ... I have clinicians saying to me, "I don't need to log that with VAD-IMS because I'm not able to accept a first request. So, as far as I'm concerned, I've given them the information and passed that on". There's still that even though [they] are meant to log that as a first request. A lot of the time they'll say, "Well no, I just referred them for a discussion about the process. So, I haven't had anything to do with the first request".* [Participant 7]

Moreover, even in cases where medical practitioners were aware of their obligation to log a first request on the system, participants reported that there was confusion amongst medical practitioners about how to do so. Participants reported that some medical practitioners were uncertain about the function of a first request and that it served merely as a notification to VAD Board and did not generate a referral (e.g. to a VAD practitioner or the SWCNS).

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*It's not rocket science but apparently it is. Likewise, it's the language, it's the process. It's people can't understand that nothing is happening when, [they] had to go through a whole rigmarole to fill out the form and figure out how to upload it. And doctors have called me like, "But I can't get into VAD-IMS ... it won't let me register to VAD-IMS". You don't have to register, you just upload it ... but doctors can't get that either.* [Participant 6]

*There is confusion by doctors knowing that even if they ... [refuse] a first request [on the VAD-IMS], they often think that is a referral.* [Participant 32]

The lack of referral and connection with the system upon lodging a first request was criticised by some participants. The current system meant that patients would be waiting for someone to contact the patient as they incorrectly believed they had already started the process by making the first request. Some participants conceded that part of the issue was that practitioners were not necessarily passing on the details of the SWCNS (via the Approved Information) or making it clear to patients what their options were when their first request was refused. In some cases, this was the result of the medical practitioner being unaware of the process themselves. This in turn often led to delays in being connected with the system, which sometimes had adverse consequences for patients. Indeed, some participants reported that there have been cases where patients have deteriorated rapidly while waiting to be assessed. When this occurred, some participants reported greater pressure to progress the patient through the process to avoid them missing out on VAD. This pressure placed additional stress on both the family and health practitioners involved.

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*[Patients often think] that they've already started the process and you have to explain actually, "No, nothing's happened yet. Now we start". And the frustration that they feel. Sometimes in that two months they've deteriorated quite significantly and then it's the pressure on them and their family and it all starts.* [Participant 4]

Participants also identified broader issues in relation to terminology. When a practitioner is unable to fulfill a role under the Act because they are not a VAD practitioner or do not have the capacity to take on the patient, they are required to "refuse" a first request. However, participants indicated that the term "refuse" in relation to the first request was "loaded". It was particularly challenging for some practitioners, for example, who had a long-standing therapeutic relationship with the patient, and did not want to be seen to be abandoning them during a vulnerable time because they were "refusing" their request.

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*The word “refuse” as well ... which goes back to that referral question ... that patients of practitioners who are refusing aren’t necessarily saying, “No I don’t want anything to do with this”. They are actually just saying, “I’m not able to” ... So, the word “refusal” is a bit loaded for some of them. [Participant 20]*

Participants also reported that there were cases where a non-VAD practitioner would “accept” the patient’s first request under the misconception that in doing so they were showing support for the patient’s choice and/or indicating their potential eligibility, not realising that the process would not proceed unless they were acting as the patient’s coordinating practitioner.

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*We often hear with acceptors “No, I am accepting that my patient should be able to access that” ... “Well, that’s great, but this request is about you accepting the role of being their coordinating practitioner”. [Participant 21]*

The ability of non-qualified VAD practitioners to accept a first request was perceived to complicate the process. The policy justification for allowing a non-qualified practitioner to “accept” a request was to accommodate ‘trigger’ or ‘catalyst’ patients (i.e. patients requesting VAD who would trigger the practitioner’s participation in VAD).<sup>58</sup> However, in practice, trigger patients were thought to be rare. Indeed, practitioners were advised against accepting first requests without completing the training due to the time it takes to do the training and do the necessary referral checks.<sup>59</sup>

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*So it could be that [X is] my patient, I’ve seen her ... I’ve known her for 20 years and she ... makes a first request to me and I say, “Yes, I’m going to accept this because I’m going to go on and become your coordinating practitioner, haven’t done the training yet [X], so it’ll be a bit of a gap” ... So, the process for winding up someone and doing the training and doing referee checks and doing all the rest of it, as much as there is intention of streamlining that ... there are necessary steps that have to happen and the time that it takes to do that is well longer than the time that it takes for the average person to move through the system. [Participant 19]*

Participants observed that it was difficult to measure the extent to which patient access was affected by the first request problems. Awareness that problems exist are only known through patient accounts, and these come from individuals who were then able to connect with the system. Little was known about patients who made a first request, but nothing further occurred.

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58 Such patients typically include those who may tick all of the boxes for eligibility, long-standing patients or patients who are so adamant in their request that they serve to crystallise a practitioner’s involvement in VAD. See Rutherford, Willmott and White, n 26, 1074.

59 Such sentiments are reflected in guidance issued by the DoH which notes “[w]hile you can accept the first request without completing the mandatory approved training, you must complete the training before you can commence the assessment process for the patient ... In some cases it is better to refer the patient to the [SWCNS] who can help them find a VAD provider”. See Department of Health, *Voluntary Assisted Dying First Request* (Government of Western Australia, 2024) <<https://www.health.wa.gov.au/voluntaryassisteddyingfirstrequest>>.



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*I think because we do have cases of people who tell us that they've [made attempts] – [but these are] people who eventually find a way. So, because of those people and they tell us that they were told that they weren't eligible and nothing was done, and [the Board] didn't receive a notification of a first request we know that that's happening. But we don't know how many [people this is] happening [to] that don't then find a way, that's our problem. [Participant 23]*

Part of the rationale for the current first request process was to assist with the Board's monitoring function. But many participants observed that this policy goal was not being realised because not all first requests were being lodged, and hence there are significant data gaps.

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*We know that the system isn't working perfectly. Maybe ... we didn't come up with a very good system to start with. But what we have [is] not doing everything we wanted it to do, or it should do ... the whole thing maybe needs rethinking. [Participant 22]*

Some participants criticised the first request lodgement requirement on policy, rather than practical, grounds. They noted that having a designated notification process seemed to undermine attempts to normalise VAD and integrate it within end-of-life care as other options do not have notification requirements.

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*How much value is the recording of a first request if it doesn't go any further ... the Board often talk about the normalisation of this as a medical procedure. And I'm not sure there's anything else that happens in medicine that requires a form to be deposited somewhere to say, "I've had a request but I'm not doing anything". It just doesn't make any sense to me. [Participant 24]*

Participants noted that problems with the first request process had been previously identified, and attempts had been made to remedy confusion. For example, participants referred to efforts by the WA VAD Board to educate on this issue and that the Secretariat had modified its practices so that once a practitioner lodges a first request, the Secretariat would notify the practitioner that the lodgement of the first request was for notification purposes only, and the Secretariat would not be making any further contact with the patient. However, it was suggested that such initiatives have been largely ineffective.

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*Even though I know the Board have been trying really hard with supporting emails and sending them things, people just don't understand that nothing happens automatically. They don't get it, can't get it and I don't know what the magic fix for that is. [Participant 3]*

Despite such challenges, some participants still favoured retaining the notification obligation associated with the first request, but identified a need for further steps to improve the current approach. Strategies identified included introducing a referral system and further educative efforts.



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*I think a change to capture the referral form process has always been my biggest ticket item ... complete all of these details, submit your form to the Board. Would you like to refer your patient to the Care Navigator? ... No obligation to do it but an option ... There is [also] many different points of education. So ... for me it would be one of those things that there is not just one golden solution that will fix everything, it's little pieces altogether that would contribute towards that.*

[Participant 21]

### *Issues identified*

Requiring medical practitioners to lodge first requests is an important data source for the VAD Board. If accurately reported, such information will notify the Board of when patients begin the VAD process and will facilitate collection of information about the participation of practitioners in VAD in WA.<sup>60</sup> This in turn can assist the VAD Board's understanding of the demand for the service, the extent to which practitioners are refusing first requests, and information about the length of a patient's VAD journey. However, evidence suggests that the first request process is currently poorly understood, and medical practitioners are not always complying with their obligations. Accordingly, the desired information from the first request process is not being captured in practice.

This also has downstream effects. As patients (and their loved ones) are commonly not given the Approved Information, nor receive clarification about the first request process, they often mistakenly believe they have commenced the process or have been connected with the system, when this is not the case. This has led to delays and, in some cases, patients have deteriorated to a point where they are no longer eligible for VAD.

### *Recommended responses*

Although there were differences in participants' views about the utility and workability of the first request process, on balance, the authors consider it should be retained. However, to achieve its intended objectives, the current difficulties with how the first request process is operating in practice should be addressed. A multifaceted approach is required. Specific training and education about medical practitioners' obligations on receiving a first request are needed. This should address issues such as the nature of a first request, legal reporting duties, obligations to provide information to the patient and terminology. This training and education should be directed at the medical profession as a whole given this knowledge needs to penetrate beyond existing VAD providers.

The authors also recommend that revisions to the existing system design should be implemented to support effective connections of the patient to the system after a first request has been made. This could include an optional referral to the SWCNS, whereby the practitioner receiving the first request asks whether the patient is willing for their contact details to be passed onto the SWCNS. Consideration should also be given to whether legislative change might be needed to facilitate this, in addition to any changes to consent policies and processes to enable this occur.

## **Recommendation 4**

**Through training and education, improve medical practitioner awareness of the first request process and how to respond appropriately.**

## **Recommendation 5**

**Improve system design so that a patient who makes a first request is connected with the VAD system.**

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60 Explanatory Memorandum Voluntary Assisted Dying Bill 2019 cl 21.

## 2.3 Individual conscientious objection

The WA VAD Act offers protections to individual health practitioners who have a conscientious objection to VAD. It permits them to refuse to participate in the request and assessment process; prescribe, supply or administer the VAD substance; and be present at the time of administration of the VAD substance.<sup>61</sup> However, as discussed above, medical practitioners who refuse a first request are required to notify the patient of their refusal and provide them with the Approved Information immediately.<sup>62</sup> Similarly, if medical practitioners receive a referral for a consulting assessment from a VAD coordinating practitioner, they must refuse the referral and notify the coordinating practitioner and the patient of their refusal immediately.<sup>63</sup> Professional obligations in relation to conscientious objection are set out in relevant health professions' codes of conducts,<sup>64</sup> and various guidance documents developed by the DoH, which indicate that those claiming a conscientious objection must not "unduly delay a patient's access to VAD"<sup>65</sup> or "inhibit a person's access to [VAD]".<sup>66</sup>

The need to respect all persons' culture, religion, beliefs, values and personal characteristics is one of the guiding principles of the WA VAD Act.<sup>67</sup> While it is widely recognised that some form of protection of conscientious objection is important, in the absence of obligations or systems to facilitate patient access, or in the event of non-compliance with such obligations, patients' access to VAD can be unduly and inappropriately compromised.

### *Participants' submissions and evidence*

Conscientious objection and health practitioners' willingness to participate in aspects of the VAD process exists across a spectrum.<sup>68</sup> Some participants identified cases where conscientious objectors to VAD still supported their patients. Indeed, participants described cases where health practitioners with a conscientious objection were directly referring their patients to VAD providers (despite having no legal obligation to do so). In some cases, conscientious objectors were still willing to offer forms of moral support to their patients notwithstanding their decision to access VAD.

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*[Our] GP, was very supportive, but he didn't like the idea of [VAD because of his] religious faith ... but he didn't allow that to influence [the patient]. He just said to [the patient] ... "There could be other ways" ... "We won't let you be in pain", all of that sort of thing ... [The GP] gave us the [SWCNS] number to ring. And we were in very close contact with him. As I said, although he's not a personal friend, he was visiting on weekends just because he liked [the patient], he liked talking about all sorts of things with him and it always came up in discussion. [Participant 34]*

*So, in our hospital in [Regional Town] we had a lot of referrals from conscientious objectors [to one of the VAD practitioners and VAD Regional Lead]. [Participant 31]*

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61 Voluntary Assisted Dying Act 2019 (WA) s 9(1).

62 Voluntary Assisted Dying Act 2019 (WA) s 20(5).

63 Voluntary Assisted Dying Act 2019 (WA) s 31(5).

64 See, for example, Medical Board of Australia, *Good Medical Practice: A Code of Conduct for Doctors in Australia* (Australian Health Practitioner Regulatory Agency, 2020) <<https://www.medicalboard.gov.au/Codes-Guidelines-Policies/Code-of-conduct.aspx>> section 3.4; Nursing and Midwifery Board of Australia, *Code of Conduct for Nurses* (Australian Health Practitioner Regulatory Agency, 2018) <<https://www.nursingmidwiferyboard.gov.au/Codes-Guidelines-Statements.aspx>> section 4.4; Pharmaceutical Society of Australia, *Code of Ethics for Pharmacists* (2017) <<https://www.psa.org.au/practice-support-industry/ethics/>> care principle 2.

65 WA VAD Guidelines, n 49, 31, 45.

66 Department of Health, *Providing Voluntary Assisted Dying in Western Australia: Health Professional Participation* (Western Australian Government, 2022) <<https://www.health.wa.gov.au/~media/Corp/Documents/Health-for/Voluntary-assisted-dying/Health-Professional-Participation.pdf>> 3.

67 Voluntary Assisted Dying Act 2019 (WA) s 4(1)(k).

68 CM Haining and LA Keogh, "I Haven't Had to Bare My Soul, But Now I Kind of Have To": Describing How Voluntary Assisted Dying Conscientious Objectors Anticipated Approaching Conversations with Patients in Victoria, Australia" (2021) 22 *BMC Medical Ethics* 149; R McDougall and D Ko, "Eligibility and Access to Voluntary Assisted Dying: A View from Victoria, Australia" (2021) 47(10) *Journal of Medical Ethics* 676, 676; Rutherford, Willmott and White, n 26, 1073.

Participants across multiple stakeholder groups identified instances where conscientious objectors were obstructing access (overtly or covertly).<sup>69</sup> The absence of requirements on conscientious objectors to provide information about VAD (except for when a patient makes a first request) and/or refer them on to another colleague without a conscientious objection or health service that provides VAD has potential to impact access.<sup>70</sup> While the absence of such obligations could affect access, the mere presence of obligations does not guarantee compliance. Indeed, participants observed that the legal and professional obligations that are already in place (described above) were not always being complied with in practice. Indeed, participants observed that some conscientious objectors were shutting conversations down and failing to provide the Approved Information (when required), which made it difficult for patients to connect with the system.

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*We then went to Mum's doctor, and her doctor refused to talk to her about it because of his religion and his beliefs. He didn't give her ... and I only found out afterwards ... that doctors were supposed to give them information. Mum wasn't given anything. [Participant 8]*

Participants also observed cases where conscientious objectors exhibited varying levels of hostility towards patients for choosing VAD. This manifested variously including withdrawing forms of care, attempting to persuade people out of pursuing VAD, displaying unsupportive attitudes and making negative comments.

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*[Some doctors are] ferociously backing away from the patient and saying, "I no longer care for them if they want to explore this". [Participant 3]*

*One of the palliative care nurses ... [who was] a conscientious objector to VAD, came in rudely and abruptly to doublecheck. And [the patient] informed her very clearly that [he], "Absolutely [wanted to access VAD, why] won't you listen to me?" ... so that put her in her place and off she went, but yeah, she had a bad attitude. [Participant 35]*

*After a fall, he did have a head scan [that] showed that there was a bit of a bleed. And the doctor kind of said flippantly, "If you're going down VAD, there's no point really doing any treatment, like why don't you just stop the Warfarin?"<sup>71</sup> I don't think the doctor understood that we don't actually want him to die from a brain bleed ... like he wants to go on his own terms ... I think just because the oncologist specialises in chemotherapy, and once that chemotherapy was withdrawn, he kind of washed his hands of the care. [Participant 2]*

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69 The impacts of individual conscientious objection have been observed elsewhere see Rutherford, Willmott and White, n 26, 1068-1069; Victorian Voluntary Assisted Dying Review Board, *Report of Operations: January 2020- June 2020* (2020) <<https://www.safercare.vic.gov.au/best-practice-improvement/publications/VADRB-january-to-june-2020>> (Victorian VADRB January 2020- June 2020) 2; Victorian Voluntary Assisted Dying Review Board, *Report of Operations: January 2021- June 2021* (2021) <<https://www.safercare.vic.gov.au/best-practice-improvement/publications/voluntary-assisted-dying-report-of-operations-january-to-june-2021>> (Victorian VADRB Report January 2021- June 2021) 19; Victorian VADRB Report July 2021-June 2022, n 26, 26-27.

70 I Kerridge et al, "Conscientious Objection and Institutional Objection to Voluntary Assistance in Dying: An Ethico-Legal Critique" (2023) 30 *Journal of Law and Medicine* 806; R McDougall and B Pratt, "Too Much Safety? Safeguards and Equal Access in the Context of Voluntary Assisted Dying Legislation" (2020) 21 *BMC Medical Ethics* 21; Rutherford, n 30; Rutherford, Willmott and White, n 26, 1072-1073.

71 Medication used to prevent blood clots.

Participants also reported challenges with some non-participating medical practitioners commenting on a patient's prospective eligibility. In some cases, this resulted in delays to access, particularly if the practitioner suggested that the patient was unlikely to meet the eligibility criteria (e.g. because they were unlikely to die within the required timeframe). Participants noted that while, in some cases, this may have been done with good intentions (e.g. to manage expectations), there were cases when participants perceived that conscientious objectors intended to subvert the process and steer people away from VAD.

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*Often, I will meet patients or family ... who've been told by a non-VAD participating practitioner that they're not eligible ... Sometimes that's valid, but obviously not the law. Sometimes it's just not valid ... [and] whether it is or isn't intended, [it] has a knock-on effect of delaying the process and delaying a person's access to assessment. [Participant 5]*

*[Some doctors say to patients] "You won't be eligible [for VAD] anyway, there's no point", and a whole host of permutations of those conversations. Sometimes done with good intention, sometimes not. [Participant 3]*

Participants also reported cases where medical practitioners refused to provide, or delayed, access to clinical information. While VAD practitioners are sometimes able to make VAD assessments without seeking additional clinical information, this is not always possible. Access to clinical information is important in cases where the practitioner does not have a pre-existing therapeutic relationship with the patient (which is often the case in practice), is not familiar with the patient's disease, in complex cases where specialist input is needed, or in cases where the patient's medical records are not up-to-date or are incomplete. While in some instances, participants suggested that delays accessing information were for administrative reasons and not intentional, participants also identified cases where practitioners would refuse to provide clinical information on the basis that it would be used to inform a VAD assessment. This was particularly challenging in regional settings due to the dearth of available specialists.

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*Access to clinical information full stop. We know that there are providers who no matter who asks them, they will not provide medical information in relation to their patient. [Participant 3]*

*I just want to say rural areas – the issue I have with prognostication is you've got a very limited pool of specialists, and you may need a specialist to give the prognosis. And if your regional specialist is a conscientious objector, it makes it quite difficult ... A lot of specialists don't want to see a patient if it's only about prognostication for VAD. I had this issue early on with a neurological case. I got turned down by four different neurologists in Perth, and my regional neurologist was a conscientious objector. [Participant 31]*

This unwillingness to provide clinical information was also reported as particularly difficult in complex clinical cases (e.g. when the patient had a rare disease or an unclear prognosis). In such cases, VAD practitioners could be left in a vulnerable position if they found a patient to be eligible without accessing such information. Participants reported that, over time, there has been an increasing number of instances where medical practitioners, unsupportive of VAD, would not provide clinical information (despite discussions about patient trajectory being customary in multidisciplinary teams in the health service setting), but then seek to challenge eligibility assessments made by VAD practitioners on the basis that such assessments were made in the absence of necessary clinical information.

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*[If the VAD practitioner] know[s] the person's treating specialist or the organisation that they work for is not supportive of VAD, it leaves that doctor very vulnerable if they find them to be eligible, when the specialist knows they haven't given them anything ... when the specialist is clear in the fact that they don't support VAD. We have certainly had people indicate that a patient's prognosis is unlikely to be within the window. Often with very strong language around that, [and] practitioners don't feel comfortable making an alternative finding. [Participant 3]*

Participants observed that some of the issues with conscientious objection related to the lack of recourse available to patients, and perceived lack of consequences for the conscientious objector in cases of non-compliance.

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*I think there's a lot of comments that get made to patients in those settings that are totally inappropriate but have no recourse. If your [community-based] nurse tells you that you shouldn't be doing VAD because that's not where you are, what do you do about that? You just pretend you didn't hear it. [Participant 6]*

*There's no teeth in this; there is no one to monitor it. [Participant 30]*

Some participants supported greater enforcement of sanctions, while others supported a softer educative approach to achieve a cultural shift.

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*So, there are soft tricks that you can do. Like when I tell my GPs that I'm going to be possibly doing this, I send them a card in the mail, not an email from a hospital... But we could, as these quiet, gentle, sneaky death doctors, transform and make people be more [acceptive of VAD] ... and not beat them with the stick ... [and] threaten them with legal stuff. [Participant 32]*

*I think there's potentially a lot of on the ground work that could be done to promote those kind of culture champions. Because I think even one of our practitioners gave us example ... that at one of our public hospitals we have a number of [practitioners from speciality X] that are trained, but at the other metropolitan public hospital – which is only however many kilometres down the road – they have no [practitioners from speciality X] that are trained because the head of the department is a conscientious objector. So, if there was a culture champion in both of those settings would we see that kind of representation from both of them? [Participant 21]*

Participants also noted that, in practice, conscientious objection was not only being claimed by health practitioners but also by administrative and executive staff, which had downstream effects.

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*[Conscientious objection is also there] in terms of people ... within health settings that may not have any direct interface with voluntary assisted dying ... they're not a practitioner and they were not receiving requests. [Participant 19]*

### *Issues identified*

The authors support legislative protection of individuals who conscientiously object to participating in the VAD process. However, the above evidence suggests that the conduct of some conscientious objectors has resulted in barriers to reasonable and timely patient access to VAD. There is also evidence that some conscientious objectors, upon hearing of the patient's desire to access VAD, have engaged in conduct that may be deemed as unprofessional when interacting with patients (and their loved ones) as well as members of the VAD workforce. These behaviours range from attempts to actively dissuade people from seeking VAD, withdrawal of other forms of care, to hostile encounters.

### *Recommended responses*

While conscientious objectors should not be expected to directly participate in the assessment, dispensing and administration aspects of the VAD process, conscientious objectors should not interfere with the ability of other health practitioners to do so. A conscientious objector should also not deprive a patient or another health practitioner of information that is necessary for the patient to access VAD.

To address these concerns, the authors make two recommendations. First, when a patient asks a medical practitioner for information about VAD, the authors believe that medical practitioners should provide such information to the patient. This information already exists in the form of Approved Information discussed above. This duty currently exists in relation to first requests made to medical practitioners, so this recommendation proposes a limited extension to that existing duty. This helps ensure that patients asking about VAD will be connected with the system.

The second recommendation is that medical practitioners should also be obliged to provide to other medical practitioners, on their request (and with the patient's consent), relevant clinical information to facilitate VAD eligibility assessments. The transmission of clinical information about a patient is a reasonable requirement to ensure a patient's eligibility for VAD can be assessed accurately and in a timely manner.

The optimal response to address both issues is to make minor amendments to the WA VAD Act to impose obligations on medical practitioners to:

- provide Approved Information about VAD if the patient seeks such information (not just in cases of a first request); and
- provide clinical information about the patient or access to the patient's medical records, as soon as practicable, upon receiving a request by a medical practitioner assessing a patient's eligibility for VAD (and with the patient's consent).

However, there are also a range of other strategies to address these issues, one of which is to draw on existing ethical duties. As mentioned above, medical practitioners are currently required by their medical codes of conduct not to impede or delay patient access to a service because that service conflicts with their own conscience. Education about how these and other ethical duties apply in the context of VAD is likely to assist in addressing these issues. Such education should also include the emerging evidence (as outlined above) of the harm caused to patients when their access to VAD is hindered. Given medical practitioners' commitment to patient-centred care, deeper understanding of these harms should assist in shifting practice.

Guidance by the DoH in relation to conscientious objection (discussed above) should be strengthened so, in addition to reminding health practitioners of their obligations not to impede access, health practitioners are actively encouraged to provide general information about VAD to patients who request it. In addition, DoH should develop additional standardised resources providing general information about the VAD process which could be made available to patients (e.g. in waiting rooms via a short pamphlet or an information card with the contact details of the SWCNS as used in other jurisdictions). DoH guidance should also encourage health practitioners to provide relevant clinical information about the patient to medical practitioners for the purpose of a VAD eligibility assessment.

## Recommendation 6

Develop strategies to ensure medical practitioners provide Approved Information about VAD to a patient who asks for information about VAD (and not just in cases of a first request).

## Recommendation 7

Develop strategies to ensure medical practitioners provide, as soon as practicable, clinical information about the patient or access to the patient's medical records (with the patient's consent) to a medical practitioner assessing their eligibility for VAD.

### 2.4 Institutional objection

The WA VAD Act is silent on the participation of institutions (such as health services, hospices, aged care facilities and community nursing organisations) in VAD. The WA VAD Guidelines acknowledge that entities may have different levels of participation in VAD due to the organisation's views on VAD or other reasons (e.g. resourcing).<sup>72</sup> The Guidelines stipulate that entities should ensure that their staff are aware of the WA VAD Act (and their obligations under it), the VAD process itself, VAD statewide services, and have access to information that will support them to respond to a patient who raises VAD. In the case of WA health system entities, the *Managing Voluntary Assisted Dying Policy*<sup>73</sup> requires them to have local policies and procedures in place to manage VAD processes. Outside of this, however, no further obligations are placed on entities to facilitate access to VAD. This is different in South Australia, Queensland, New South Wales and the Australian Capital Territory where their legislation imposes certain obligations on objecting institutions.<sup>74</sup>

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<sup>72</sup> WA VAD Guidelines, n 49, 12.

<sup>73</sup> Department of Health, *Managing Voluntary Assisted Dying Policy (MP 0154/21)* (Government of Western Australia, 2021) <<https://www.health.wa.gov.au/~media/Corp/Policy-Frameworks/Clinical-Governance-Safety-and-Quality/Managing-Voluntary-Assisted-Dying-Policy/managing-voluntary-assisted-dying-policy.pdf>> (*Managing VAD Policy*). Page 4 of the Policy defines WA health system entities to include Health Service Providers established under section 32(1)(b) of the *Health Services Act 2016* (WA) and the DoH as an administrative division of the State of WA pursuant to section 35 of the *Public Sector Management Act 1994* (WA). Contracted health entities are not considered WA health system entities.

<sup>74</sup> See *Voluntary Assisted Dying Act 2021* (Qld) pt 6 div 2; *Voluntary Assisted Dying Act 2021* (SA) pt 2; *Voluntary Assisted Dying Act 2022* (NSW) pt 5; *Voluntary Assisted Dying Act 2024* (ACT) pt 7. For a comprehensive overview of all of the State VAD laws and a description of the obligations placed on entities not participating in VAD see K Waller et al, "Voluntary Assisted Dying In Australia: A Comparative And Critical Analysis of State Laws" (2023) 46(4) *University of New South Wales Journal* 1421, 1455-1462.



## Participants' submissions and evidence

There have been multiple reports of institutional objection to VAD in WA.<sup>75</sup> Objection to VAD has occurred in health services, hospices, aged care and community care settings. Institutions have varied with respect to their level of support for VAD as well as the nature of the limitations they place on VAD activities that are permissible on site. Unsurprisingly, participants reported that some institutions prevented institutional staff from being involved in the VAD process. However, many also reported restrictions on the ability of external health practitioners to visit patients or residents in these institutions to provide VAD services. Some commented that this prohibition on participation also extended to information provision or counselling. In the view of one participant, institutional objection had a greater potential to affect VAD access than an individual conscientious objector.

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*[The conscientious objector] was a horrible nuisance, but it was mainly the total hospital's policy statement that worried me more because that was just a solid brick wall. [Participant 35]*

Participants observed that institutional objection can create significant barriers to access and worsen family caregivers' grief in some cases.<sup>76</sup> Participants described that institutional objection often meant patients needed to be transported or transferred out of the institution for aspects of the process. In some cases, institutional objection necessitated workarounds, requiring aspects of the VAD process to occur behind closed doors within the objecting institution, in gardens, carparks and local schools. However, in cases where the family could not afford a taxi to move to a new facility or the patient's condition deteriorated significantly, transfers and workarounds were not possible. These patients were denied the ability to access VAD and would be required to pursue care and treatment options they perceived to be less favourable.

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*I was very concerned about moving [the patient] ... he was really immobile, which was why there was no way he could ever come home. I was really concerned as to how I was going to get him off the hospital grounds and I said that to VAD Statewide Care Navigator ... even though his mind is [good] ... he's not physically. The ambulance transfer financially ... would have been about \$1,100 to get him there and back and we had to do that four times. That would have been the only way ... [t]hat really wasn't financially an option for us to do that. [Participant 35]*

In addition to the logistical challenges, participants reported that due to an institutional objection (or opposition within a particular health service unit), patients who raised VAD were often met with hostility or had their conversations concerning VAD shut down. This was reported to disrupt continuity of care and damage therapeutic relationships.

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75 Haining, Willmott and White, n 4, 737-738; *WA VADB 2022-2023 Report*, n 13, 53; G Adshead, "Perth Man's Battle to Die with Dignity Despite Being Approved Under Voluntary Assisted Dying Laws", *6PR Perth*, 3 September 2021 <<https://omny.fm/shows/6pr-mornings/perth-mans-battle-to-die-with-dignity-despite-bein->>; *My Stop: Gina's Story*, n 15; A Brennan, "Concerns Raised About Access to Voluntary Assisted Dying in Western Australia", *NCA NewsWire*, 29 November 2023 <<https://www.news.com.au/lifestyle/health/concerns-raised-about-access-to-voluntary-assisted-dying-in-western-australia/news-story/9c3e61e5b1c06b52f0ea6242e89e1079->>; J Dietsch, "Voluntary Assisted Dying Board Chair Scott Blackwell Says Some Hospitals Blocking Access to Procedure", *The West Australian*, 29 November 2023 <<https://thewest.com.au/news/health/voluntary-assisted-dying-board-chair-scott-blackwell-says-religious-hospitals-blocking-access-to-procedure-c-12563909->>; Parish, n 15.

76 The impact of institutional objection in the context of VAD laws in Australia has been discussed elsewhere see, for example, Haining, Willmott and White, n 4, 737-738; McLaren and Mewett, n 30,116; White et al, n 26, 212-214; BP White et al, "The Impact on Patients of Objections by Institutions to Assisted Dying: A Qualitative Study of Family Caregivers' Perceptions" (2023) 24 *BMC Medical Ethics* 22; White, Jeanneret and Willmott, n 23, 2702; *Conference Report: VAD CON 2023*, n 23, 8,10; *Victorian VADRB January 2020 - June 2020*, n 69, 2; *Victorian VADRB Report July 2021-June 2022*, n 26, 26-7; *Victorian VADRB Report July 2022- June 2023*, n 26, 27-8; *WA VADB 2022-2023 Report*, n 13, 53; Brennan, n 75; Dietsch, n 75.



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*I am almost in tears just remembering all the cases, all the people that have suffered at the hands of [Religious Institution X]. And it's not good ... it is terrible ... I've had patients, one particular woman with a terrible fungating cancer ... in a terrible state. She tried to raise VAD when she was an inpatient ... and just got short-shift and was so scared of raising it again with anyone ... it all came out how awful they were to her because she'd raised that. I've had other patients also who have gone into [particular institutions] with symptom control have come out again, come and seen me ... and [told] me just the most awful [things] – they're just cut off and shut up, shut off.*  
[Participant 28]

Participants were also critical about the fact that institutions were not transparent about their degree of participation in the VAD process. Some institutions provided no (or minimal) insight into the degree to which VAD activities were permitted onsite. It was reported that some institutions would adopt a broader faith-based position and not provide detail about how this had been operationalised in the institution. There was even a suggestion that some institutions were still yet to form a position on VAD.

One participant criticised an institution's position statement that suggested it was supportive of VAD on the basis that such support was not reflected in practice, citing examples of the institution's staff exhibiting hostility towards patients wishing to access VAD and withdrawing other forms care.

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*I accept at the end of the day [religious health services are] not authorised to help in any way, shape or form, but they should still nevertheless be pleasant to the patient ... [T]hey shouldn't withdraw any of their normal palliative services to the patient. They shouldn't in any way penalise the patient just because they are aware that person is seeking VAD. The Code of Conduct reads absolutely stunningly beautifully, for an institution that's actually totally opposed to VAD. Unfortunately, [it] doesn't always happen on the ground like that.* [Participant 13]

Participants observed that the lack of transparency by some institutions had made it difficult for patients to make informed choices about their care options prior to admission.<sup>77</sup> Consultation undertaken by the statewide services in the early stages of the regime provided an indication of the limitations of some institutions. However, information about the level of participation of institutions was not publicly available or easily ascertained, given institutions were not always transparent about the extent to which they permitted VAD activities on site (if at all). Participants suggested that there had been efforts made by advocacy organisations to try and map out institutions and their position on VAD in WA, but the lack of input by institutions to inform this map has presented difficulties.<sup>78</sup>

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*It is a serious problem, I think. And the fact that the Statewide Care Navigator Service won't publish a list of the institutions that are not VAD friendly, if I can put it like that, also makes it very difficult for people to make a decision about where they want to go if they have to move to an institution. That should be public information on everybody's website, and freely available as part of the package that goes to GPs' offices.* [Participant 15]

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77 Such sentiments about the impact of lack of transparency by institutions in relation to VAD have similarly been reported elsewhere see E Close et al, "Institutional Objection to Voluntary Assisted Dying in Victoria, Australia: An Analysis of Publicly Available Policies" (2023) 20(3) *Journal of Bioethical Inquiry* 467, 478; White et al, n 76, 4-5,11; *WA VADB 2022-2023 Report*, n 13, 53; Brennan, n 75; Dietsch, n 75.

78 Efforts to map out levels of participation of aged care facilities in VAD has been done in Victoria by Dying with Dignity Victoria. See Dying with Dignity Victoria, *VAD and Aged Care Facilities* <<https://www.dwdv.org.au/our-services/vad-and-aged-care-facilities/>>.

Participants also reflected that there was currently limited scope for recourse. One option noted was for patients to complain to the institution itself. However, such recourse was considered suboptimal as not everyone would feel comfortable to do so or know how to make a complaint. Participants also suggested that some families thought that complaining about an institution once their loved one had died was futile. Others felt a complaint would be ineffective to change the institution's stance on VAD. Nevertheless, participants cited examples where families had gone to media (or threatened to do so), which resulted in some success. They also gave other examples of cases that were escalated with no success.

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*Despite one of my patient's relatives escalating a complaint through all the appropriate channels ... nothing's been done about it and it's disgusting, and ultimately should be changed.*

[Participant 33]

*Because when the CEO made it clear that they had world's best practice in palliative care and wouldn't interfere with a patient coming in and out, there was no point. If the head honcho said that a doctor's not going to visit, well, there was no point in having any further consultation or requests. [Participant 35]*

Participants noted that patients often had limited choices when it came to institutions, because many facilities were faith-based and not supportive of VAD. This left patients who were unable to access VAD within the community with limited options.

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*Accommodation is something that comes up for us all the time. "I want to die. I can't die at home". Getting access to a bed in a public hospital is a nightmare. Most of our hospices are faith-based. Where can I go and how can I access it? [Participant 3]*

Some participants expressed frustration that publicly funded institutions were able to opt out of delivering a lawful medical service. Many participants considered reform of how institutional participation is currently regulated necessary. When expressing such views, participants often referred to legislative models in other Australian states as preferable to WA's current regulatory approach. In particular, the Queensland model was favoured amongst participants. Many participants expressed a desire for greater transparency from institutions about what VAD activities would be permitted onsite, and a requirement for institutions to allow access to VAD (acknowledging that its own staff would not be required to participate in the process).

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*My view is if you get Government funding, you implement the Government policy and you implement the Government legislation ... That's the simple thing for me is that you – yes, they're going to use religious whatever, I get that. But I don't know, it doesn't sit well with me that they get funding to deliver a service, but they're not prepared to deliver this service. So, I think the Government has an opportunity to put it into their contracts. [Participant 25]*

*Institutional conscientious objection ...it's a big one. It's easily addressed in a way, noting that I think it's South Australia, Queensland and New South Wales that have included in their legislation quite comprehensive provisions detailing what are the obligations of particularly of aged care facilities that are not hospitals ... [S]ome or a combination of those types of provisions should be adopted and added to our Act ... the Queensland provisions may be the best. [Participant 14]*

### *Issues identified*

Participants identified institutional objection as a significant access barrier to VAD and the cause of suboptimal care and experiences for patients and their loved ones. These views accord with Australian evidence about the harms of institutional objection, in settings where institutional objection is regulated by policy alone.<sup>79</sup> They are also consistent with views of the WA VAD Board.<sup>80</sup> WA's current policy approach to regulating institutions has not been effective in addressing these concerns.

### *Recommended responses*

A new approach to regulating institutional objection is needed in WA. The WA VAD Act should be amended to impose obligations on institutions to facilitate better patient access to VAD. The stronger force that is associated with legislative mandate rather than policy direction is needed to shift institutional behaviour on this issue.<sup>81</sup> Having legal obligations imposed on an institution, as opposed to guidance in a non-binding Government policy, can assist an individual to advocate for their choice and, to an extent, address power and resource imbalances between large institutions and terminally ill individuals. The force of law may also be needed to direct institutions with deeply-held views including those stemming from religious faith, to act in particular ways.<sup>82</sup>

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79 BP White et al, "Legislative Options to Address Institutional Objections to Voluntary Assisted Dying in Australia" (2021) 3 *UNSW Law Journal Forum*; Haining, Willmott and White, n 4, 737-738. White et al, n 76; White et al, n 26, 212-213.

80 *WA VADB 2022-2023 Report*, n 13, 53.

81 White et al, n 79; Close et al, n 77, 480.

82 Close et al, n 77, 480; White et al, n 79.

A legislative model should balance competing interests and aim to ensure that patients who want VAD can have access to VAD, but not require institutions or their staff to directly participate in VAD. Similar to the views of some participants, the authors favour a modified Queensland approach. To provide some context, under Queensland legislation, entities<sup>83</sup> (and their staff) are not obliged to actively participate in the VAD request, assessment or administration process. However, obligations are placed on entities to facilitate access, at least to some extent. These obligations vary depending on whether the facility is residential or non-residential (and in cases of residential facilities whether the person is a permanent or non-permanent resident). All entities must disclose publicly if they do not provide VAD services.<sup>84</sup> They must also allow relevant health practitioners to visit residents who request information about VAD and permit them (with eligible witnesses) to make VAD requests (including first, second and final requests).<sup>85</sup> In the case of residential settings (including aged care facilities and nursing homes), if the person is a permanent resident, the facility must allow access to relevant health practitioners onsite so eligibility assessments (including referral of determinations) and the administration decision can take place, or facilitate transfer if a practitioner is unable to attend.<sup>86</sup> Administration of the VAD substance must also be permitted onsite.<sup>87</sup> In cases of non-permanent residents, the facility must facilitate a transfer to a place where VAD assessments, the administration decision and administration can take place.<sup>88</sup> If transfer is not reasonable, then the facility must allow relevant health practitioners to come on site to carry out such activities.<sup>89</sup> Obligations in relation to non-residential facilities (e.g. public and private hospitals and hospices) mirror the obligations placed on residential facilities with respect to non-permanent residents.

The authors are of the view that the Queensland provisions that govern the ability of a permanent resident to access VAD in an objecting institution should apply across the board to all individuals seeking VAD, regardless of the nature of the institution or whether the person seeking VAD is a permanent resident. In other words, WA should amend its legislation to require all institutions to follow the position in Queensland for permanent residents. Such an approach better balances the competing interests of a person seeking VAD and the right of an institution and its staff not to provide VAD services.

Non-legislative approaches to address institutional objection should also be vigorously pursued and the authors note that some of these initiatives are capable of prompt implementation. For example, the current *Managing Voluntary Assisted Dying Policy*<sup>90</sup> which applies to WA health system entities should be amended to introduce more prescriptive requirements such as requiring a VAD service to be provided on the premises. In relation to non-WA health system entities, engagement by the DoH or the WA VAD Board is needed to consult (or further consult) with such entities about their approach to managing VAD. All entities should be made aware of evidence of significant harm that institutional objection causes, and be requested to review and, if necessary, amend local policies to address such harm. Consideration should also be given to developing a publicly available guide that outlines which entities provide VAD services or allow them to be provided on their premises. This would enable patients to make informed decisions about their care. Finally, efforts to manage institutional objection and facilitate access to VAD should be included in the Access Standard.<sup>91</sup>

## Recommendation 8

**Impose obligations on all entities providing health, aged, residential and other care to facilitate access to VAD.**

83 Entities are defined as entities other than an individual that provides a relevant service (including health service, residential aged care service and personal care service) see *Voluntary Assisted Dying Act 2021* (Qld) ss 87-88.

84 *Voluntary Assisted Dying Act 2021* (Qld) s 98.

85 *Voluntary Assisted Dying Act 2021* (Qld) ss 90, 92, 93.

86 *Voluntary Assisted Dying Act 2021* (Qld) ss 94(2), 95(2), 96(2).

87 *Voluntary Assisted Dying Act 2021* (Qld) s 97(2).

88 *Voluntary Assisted Dying Act 2021* (Qld) ss 94(3), 95(3), 96(3), 97(3).

89 *Voluntary Assisted Dying Act 2021* (Qld) ss 94(4), 95(4), 96(4), 97(4). When assessing reasonableness consideration is given to whether transfer will cause serious harm to the person or transfer would likely adversely affect the person's access to VAD.

90 *Managing VAD Policy*, n 73.

91 The Access Standard does not currently account for institutional objection in any detail other than to "encourag[e] health providers and health services to be ready to receive enquires for information from people and their families and be able to respond in a patient-centred manner" see *Access Standard*, n 29, 2.

## 2.5 Telehealth

The Commonwealth Criminal Code makes it an offence to use a “carriage service” (such as telephone, videoconference, email or other forms of electronic transmission) to distribute material that counsels or incites committing or attempting to commit suicide.<sup>92</sup> A Federal Court decision handed down in November 2023 found that the term “suicide” can extend to voluntary assisted dying.<sup>93</sup> In practice, this means that certain aspects of the VAD process cannot be carried out via electronic communication such as telehealth and/or email.

The WA VAD Act permits certain aspects of the VAD process to be carried out using audiovisual communication, provided such communication is not contrary or inconsistent with Commonwealth law.<sup>94</sup> The WA VAD Guidelines provide guidance regarding which VAD activities may occur via audio-visual communication.<sup>95</sup> The Guidelines state that:

As a general rule, any information that relates specifically to the act of administering a voluntary assisted dying substance or provides details or instructions about the act of administering a voluntary assisted dying substance must not be discussed or shared by phone, fax, email, videoconference, internet and the like.<sup>96</sup>

Concerns about the barriers that the Commonwealth Criminal Code creates in relation to VAD provision have been raised by the WA VAD Board with the Minister for Health, Attorney General, and Chief Executive Officer of the Department of Health.<sup>97</sup> In 2024, Kate Chaney MP introduced a Bill into Federal Parliament to amend the Commonwealth Criminal Code to remove lawful VAD activity from the definition of suicide. If passed, this amendment would remove potential liability arising from VAD services being provided via telehealth.<sup>98</sup>

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92 *Criminal Code Act 1995* (Cth) ss 474.29A, 474.29B.

93 *Carr v Attorney-General* (Cth) [2023] FCA 1500, [74].

94 *Voluntary Assisted Dying Act 2019* (WA) s 158.

95 *WA VAD Guidelines*, n 49, 26-27.

96 *WA VAD Guidelines*, n 49, 8, 26.

97 *WA VADB 2021-2022 Report*, n 13, 37.

98 Criminal Code Amendment (Telecommunications Offences for Suicide Related Material—Exception for Lawful Voluntary Assisted Dying) Bill 2024.

## Participants' submissions and evidence

Participants expressed frustration about the impact of the Commonwealth Criminal Code on the practice of VAD, particularly in relation to regional patients.<sup>99</sup> Participants were also aware that only the Commonwealth Parliament could amend the Commonwealth Criminal Code and supported the lobbying efforts for legislative change by those within the WA system and Government.

However, some participants suggested that there was scope for the DoH to provide more clarity in their Guidelines about which VAD activities are permitted.

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*Telehealth is outside the control of the state. But what is within the state's control is how they word the Guidelines to doctors to work around Telehealth ... I just think that the Department needs to do a much better job in its Guidelines of helping explain to doctors how to work their way around the system. [Participant 13]*

## Issues identified

It is clear from participants' views as well as other evidence that the Commonwealth Criminal Code creates unjustifiable challenges for access to VAD, particularly for regional patients.

## Recommended responses

The authors (along with other colleagues) have previously called for the Commonwealth law to be amended.<sup>100</sup> The authors support and recommend ongoing efforts by the WA Government and those in the VAD system to advocate for this change at a federal level.

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99 For commentary about the Commonwealth Criminal Code, including its harms, see E Close et al, "Voluntary Assisted Dying and Telehealth: Commonwealth Carriage Service Laws Are Putting Clinicians at Risk" (2021) 215(9) *Medical Journal of Australia* 406; K Del Villar et al, "Voluntary Assisted Dying and the Legality of Using a Telephone or Internet Service: The Impact of Commonwealth 'Carriage Service' Offences" (2022) 47(1) *Monash Law Review* 125; K Del Villar et al, "Voluntary Assisted Dying by Practitioner Administration is Not Suicide: A Way Past the Commonwealth Criminal Code?" 29(1) *Journal of Law and Medicine* 129; K Furness et al, "The Commonwealth Criminal Code Restricts the Use of Carriage Services to Access Voluntary Assisted Dying in Victoria: A Perspective" (2022) 47(1) *Australian Health Review* 64; Haining, Willmott and White, n 10; Haining, Willmott and White, n 4, 738-739; Hunt, n 33, 208; RSW Lugg, "Voluntary Assisted Dying and Telehealth: Commonwealth Carriage Service Laws are Putting Clinicians at Risk" (2022) 216(4) *Medical Journal of Australia* 210; McLaren and Mewett, n 30, 115; Rutherford, Willmott and White, n 26, 1071; Sellars et al, "Medical Practitioners' Views and Experiences of Being Involved in Assisted Dying in Victoria, Australia: A Qualitative Interview Study Among Participating Doctors" (2021) 292 *Social Science and Medicine* 114568, 5; White et al, n 26, 212, 214; Willmott et al, "Participating Doctors' Perspectives on the Regulation of Voluntary Assisted Dying in Victoria: A Qualitative Study", n 26, 127; *Conference Report: VAD CON 2023*, n 23, 8,10; New South Wales Voluntary Assisted Dying Board, *Interim Report: Voluntary Assisted Dying in NSW (2024)* <<https://www.health.nsw.gov.au/voluntary-assisted-dying/Documents/interim-board-report-2024.pdf>> 2,4; Queensland VADRB *Annual Report 2022-2023*, n 23, 28; *South Australia VADRB Quarterly Report 31 January to 30 April 2023*, n 23, 3; Tasmanian Voluntary Assisted Dying Commission, *Report on the End-of-Life Choices (Voluntary Assisted Dying) Act 2021's Operation in its First Six Months (2023)* <<https://www.health.tas.gov.au/sites/default/files/2023-09/Voluntary-Assisted-Dying-Six-Month-Report-of-Operations-June-2023.pdf>> (Tasmanian VAD Commission *Six Month Report 2022-2023*) 11; Tasmanian Voluntary Assisted Dying Commission, *Voluntary Assisted Dying Commission Annual Report 2022-2023 (2023)* <[https://www.health.tas.gov.au/sites/default/files/2023-11/voluntary\\_assisted\\_dying\\_commission\\_annual\\_report\\_2022-23.pdf](https://www.health.tas.gov.au/sites/default/files/2023-11/voluntary_assisted_dying_commission_annual_report_2022-23.pdf)> (Tasmanian VAD Commission *Annual Report 2022-2023*) 4, 7; Victorian Voluntary Assisted Dying Review Board, *Report of Operations: June 2019- December 2019 (2020)* <<https://www.safercare.vic.gov.au/best-practice-improvement/publications/VADRB-june-to-december-2019>> (Victorian VADRB *Report June 2019-December 2019*) 10; *Victorian VADRB January 2020- June 2020*, n 69, 1, 16; Victorian Voluntary Assisted Dying Review Board, *Report of Operations: Victorian VADRB Report July 2020- December 2020 (2021)* <<https://www.safercare.vic.gov.au/best-practice-improvement/publications/voluntary-assisted-dying-report-of-operations-july-to-december-2020>> 4 (Victorian VADRB *Report July - December 2020*); *Victorian VADRB Report January 2021-June 2021*, n 69, 2, 6, 20; *Victorian VADRB Report July 2021-June 2022*, n 26, 2, 25; *Victorian VADRB Report July 2022- June 2023*, n 26, 27; Go Gentle Australia, "His Final Days were Terrible", 25 October 2023 <[https://www.gogentleaustralia.org.au/his\\_final\\_days\\_were\\_terrible](https://www.gogentleaustralia.org.au/his_final_days_were_terrible)>; Parish, n 15; J Zimmerman, "Attorney-General John Quigley: VAD Via Telehealth Ban Discriminates Against Aboriginal People, Must Be Changed", *West Australian*, 4 December 2023 <<https://thewest.com.au/politics/attorney-general-john-quigley-ban-on-vad-via-telehealth-discriminates-against-aboriginals-must-be-changed-c-12782261>>; J Zimmerman, "Voluntary Assisted Dying Laws: Federal Court Ruling on VAD Sparks Doctor Fears Over Telehealth", *The West Australian*, 2 December 2023 <<https://thewest.com.au/news/wa/voluntary-assisted-dying-laws-federal-court-ruling-on-vad-sparks-doctor-fears-over-telehealth-c-12755215>>; J Zimmerman, "Voluntary Assisted Dying: Mark McGowan Supports Dementia Sufferers Accessing VAD and Larger Telehealth Role", *The West Australian*, 28 February 2023 <<https://thewest.com.au/politics/state-politics/voluntary-assisted-dying-mark-mcgowan-supports-dementia-sufferers-accessing-vad-and-larger-telehealth-role-c-9895981>>.

100 Close et al, n 99; Del Villar et al, "Voluntary Assisted Dying and the Legality of Using a Telephone or Internet Service: The Impact of Commonwealth 'Carriage Service' Offences", n 99; Del Villar et al, "Voluntary Assisted Dying by Practitioner Administration is Not Suicide: A Way Past the Commonwealth Criminal Code?", n 99.

## 2.6 Patient-focused resources

As discussed in 1.1, access to information about VAD is necessary for awareness-raising. However, given the complexity of the VAD process, access to detailed information is also critical for patients to connect with the system and then navigate the various aspects of the VAD process.<sup>101</sup> Such information is particularly important for patients who are unable to access VAD through their usual treating doctor or from within their treating facility. Information and resources need to be readily available when sought and accessible to WA's diverse population.

### *Participants' submissions and evidence*

Participants acknowledged that there were a wide range of VAD resources available, many of which were developed by the DoH.<sup>102</sup> However, participants were of the view that resources were difficult to locate. Indeed, participants perceived that sometimes relevant information was buried within copious online resources and was couched in language that was not easily understood. Participants speculated that many documents developed by the DoH were framed to manage potential legal risk and this resulted in documents that were unnecessarily detailed and hard to understand by those needing the information.

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*The resources that we have available significantly impact on people being able to understand what VAD is and how to access it. All of the documents the Department of Health provide are incredibly challenging to read and understand for people, particularly from different cultural backgrounds where English is not their first language, where they're not particularly health literate. Even the public facing website you have to know to click on an accordion to see the list of about a bazillion information sheets. All of which you're just clicking and hoping you land on the right one in most cases. Even [VAD staff] that use them every day often are like, "I don't know which one to give them. There's too much stuff". None of them really target the information that we hear from patients they actually want. Like what does this actually mean for me and my person? How do I help support them? How do I help plan for what this could look like? Where can I take the substance? What happens after I die? ... The information isn't accessible. It's only available audibly or in the written fact sheet. There's no infographic that's useful or videos. [Participant 3]*

*The information as well that they can access, the majority of this is on the internet. Many of our patients, elderly, don't have internet access so there's no other way for them to really access the information apart from a GP [or] specialist. [Participant 4]*

*The documents have been crafted to minimise risk to the Department of Health, not to minimise risk of the voluntary assisted dying process not working effectively ... [I]f they were there to ensure that the legislation actually worked as it was intended, they would be crafted very differently. There is no such thing as six page fact sheet, and there is like no fact sheet that is under six pages because it's all full of legalese. [Participant 19]*

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101 White, Jeanneret and Willmott, n 23.

102 For information about VAD specifically directed at the community see Department of Health, *End of Life Care* (Government of Western Australia) <[https://www.health.wa.gov.au/Articles/A\\_E/End-of-life-care](https://www.health.wa.gov.au/Articles/A_E/End-of-life-care)>.



Participants had mixed views about the utility of the Approved Information that is required to be provided to a patient who makes a first request.<sup>103</sup> Some participants commented that the Approved Information document was useful and assisted patients connect with the system by providing details of the SWCNS. Although some thought that the document could be more succinct, participants felt that it effectively distilled the key steps of the process. This document, together with the guidance provided by VAD staff (e.g. VAD practitioner, SWCNS, SWPS and VAD Coordinator), helped patients to navigate the system.

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*They did have a document – I think at that time your head is in such a place that you just need something really simple. You know pages and pages of information are probably not very useful – well I didn't find. But [the document] laid out what the steps are ... [the] checklist was really helpful so that we knew what was coming next. And also being told what was coming up by the people that were helping you navigate that process. [Participant 9]*

Despite some positive feedback about the Approved Information document, participants noted that its utility relied on patients receiving it. As noted earlier, participants expressed concern that medical practitioners were not always providing it to patients, despite their legal obligation to do so. Participants also considered the document was difficult to locate through usual online searches.

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*I just found the Approved Information, and of course the first thing on page 1 is the phone number for the Care Navigators and [their] email. [It would be helpful if] that was made significantly more easily searchable ... I mean you can find this if you know where to search on the DoH website, but it does take multiple clicks along some very unfriendly looking links ... [you need a] button like, "Are you interested in information on assisted dying? Click here". Bang, done – searchable by everyone, including patients and GPs. [Participant 33]*

Participants offered several concrete suggestions to improve current resources. In addition to simplifying the content, participants suggested that resources should be available online and widely available in print form (e.g. within health services).

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*[There is a need for] clarity of information ... If there was a one page document, rather than a 16 page document. And if it had, "The Care Navigator's phone number is dot, dot, dot. If you're in hospital, ask to see a VAD Coordinator. This is what VAD is". And just really, really short and to the point I think would be really helpful. Because I go to that website to find a Navigator's phone number quite often and I struggle to find it. I know it's there, but it should be front, centre and right at the top. [Participant 6]*

*The information brochures [medical practitioners are] supposed to hand [to] patients who make enquiries about VAD ... the Department has to make sure that those brochures are replenished so that there are always a few of them available in any practice. [Participant 13]*

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103 Such sentiments reflect previous findings see Haining, Willmott and White, n 4, 737.



### *Issues identified*

Access to accurate and accessible information about the VAD process is critical for empowering patients (and their loved ones) to access and navigate the VAD process. The evidence suggests that, in their current form, patient-focused resources are not adequately achieving these objectives.

### *Recommended responses*

The authors recommend that existing resources be reviewed and revised to improve accessibility of content. Steps should also be taken to improve availability of resources. Consideration should be given to–

- ensuring resources are:
  - available in a variety of formats;
  - culturally appropriate (informed by consultation with the communities they are intended for);
  - suitable for varying levels of health literacy;
- improving search engine optimisation and mapping of websites so online resources are easily locatable; and
- ensuring that print resources are widely available across various care settings (e.g. hospitals, GP clinics).

While there are a series of commitments to facilitate access to information about VAD within the current Access Standard, revision may be helpful to highlight the need for resources to be appropriately tailored to suit a wide range of audiences. Consideration may also be given to include commitments within the Access Standard with respect to the dissemination of such information (beyond the current position of having the SWCNS as the point of contact for information).<sup>104</sup>

## **Recommendation 9**

**Review and revise the content, format and accessibility of consumer VAD resources.**

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104 For current commitments to facilitate access to information about VAD see *Access Standard*, n 29, 2.

# Chapter 3: Eligibility assessments

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Participants who participated in interviews and focus groups for the purpose of this Review were aware (and reminded at the beginning of the interview or focus group) of the Panel’s terms of reference and that the Panel was not seeking views on eligibility criteria. However, in order to provide insight into the operation and effectiveness of the Act, participants were asked to provide general views on the eligibility assessment stages of the VAD process, and challenges they identified in practice. This section provides an overview of these reflections, as well as participants’ views about the existing eligibility criteria.

## *Participants’ submissions and evidence*

### 3.1 General reflections

Some participants expressed concerns about the inflexible framing of the eligibility criteria. Reference was made by some to legislation in some other states that allowed applications for exemption if the person did not satisfy the eligibility criteria relating to the person’s medical condition (Tasmania)<sup>105</sup> or citizenship or residence (Queensland,<sup>106</sup> New South Wales<sup>107</sup> and Australian Capital Territory<sup>108</sup>).

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*Tasmania has an exemption process, and I would love an exemption option because I think that’s probably what our legislation doesn’t have. [Participant 6]*

Another challenge participants noted was in relation to managing changes in eligibility once a person was assessed as being eligible for VAD. This typically arose when patients subsequently lost decision-making capacity or, less frequently, when they were no longer expected to die within the prognosis window. These situations were especially concerning for practitioners if the patient was already in possession of the VAD substance.<sup>109</sup> The lack of guidance regarding what should be done in such cases was reported to be a source of distress for VAD practitioners, loved ones of the patient and others involved in the patient’s care (e.g. hospital treating team and community nursing staff).

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105 Section 6(3) of *The End-of-Life Choices (Voluntary Assisted Dying) Act 2021* (Tas) permits the VAD Commission (similar body to the WA VAD Board), on application of the person, to provide an exemption if they do not have a disease, illness, injury or medical condition that is expected to cause death within 6 months, or 12 months if neurodegenerative.

106 In Queensland, a person may apply to the chief executive for an exemption for Australian residency and local residency requirements. The chief executive must grant an exemption if satisfied that the person has a substantial connection to Queensland and there are compassionate grounds for granting an exemption: *Voluntary Assisted Dying Act 2021* (Qld) s 12.

107 In New South Wales, a person can apply for an exemption in relation to the requirement to be ordinarily resident in New South Wales for 12 months. The New South Wales VAD Board must provide an exemption if satisfied that the person has a substantial connection to New South Wales and if there are compassionate grounds: *Voluntary Assisted Dying Act 2022* (NSW) s 17.

108 In the Australian Capital Territory (ACT), when the Act comes into force, the director-general must grant an individual an exemption from the eligibility requirement that requires an individual to have lived in the ACT for the previous 12 months if the individual is found to have had a substantial connection to ACT. See *Voluntary Assisted Dying Act 2024* (ACT) ss 11(1)(f)(i), 154.

109 Similar concerns have been raised in Tasmania where the legislation is silent: *Tasmanian VAD Commission Annual Report 2022-2023*, n 99, 28; *Tasmanian VAD Commission Six Month Report 2022-2023*, n 99, 21.

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*[In relation to] management of change in eligibility ... I think our practitioners are very, very vulnerable in that space. Because there is nothing in our Act that speaks to assessment of changing eligibility or how that could be managed. So, it's up to the individual provider to make their own determination about what they do, which is really, really difficult. [Participant 3]*

Participants also identified that there was some confusion in relation to the reporting obligations placed on VAD practitioners when seeking input from others to determine eligibility and the referral for determination process. The WA VAD Act requires VAD practitioners to make a referral for determination when they are unable to determine a patient's decision-making capacity, prognosis, or whether they are acting voluntarily and without coercion.<sup>110</sup> The referral must be made to an individual with the appropriate skills and training to make that determination.<sup>111</sup> The requisite forms which the coordinating and consulting practitioners need to fill out (i.e. First Assessment Report Form and Consulting Assessment Report Form respectively) require the practitioners to document whether a referral for determination was made when assessing the patient's eligibility. In practice, the ways in which VAD practitioners were seeking information from other medical practitioners varied, ranging from proactively seeking specialist information to help inform eligibility to cases where specialist input was sought due to uncertainty. Participants reported that medical practitioners had a poor understanding of what constituted a referral for determination under the WA VAD Act and what needed to be documented. Some participants surmised that this poor understanding of this process meant that, in some cases, VAD practitioners were not documenting specialist input which would constitute a formal referral for determination because they mistakenly believed that it was not such a referral.

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*I know that there's some different ways that the processes work in terms of practitioners gathering information in order to have a background on a patient and undertake a first assessment, which they will then come to a decision on versus practitioners who will undertake a first assessment, and then go out and seek a referral to another practitioner for a determination in relation to criteria ... I say this just because we don't have specialists involved in the process ... but we are aware that practitioners are seeking specialist opinions around prognosis ... I think that's happening more than we are aware in the sense that not all of that's being documented as a referral for determination. [Participant 19]*

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<sup>110</sup> *Voluntary Assisted Dying Act 2019* (WA) ss 26, 37.

<sup>111</sup> *Voluntary Assisted Dying Act 2019* (WA) ss 26, 37. In cases of a referral for prognosis and decision-making capacity the referral must be to a registered health practitioner. In cases of a referral for determination for the purposes of assessing voluntariness, this may be made to any person with the appropriate skills and training and including, for example, social workers and police officers. See *WA VAD Guidelines*, n 49, 42.

## 3.2 Reflections on specific eligibility criterion

### Prognosis

Under the WA VAD Act, a person is required to have a disease, illness or medical condition that will, on the balance of probabilities, cause death within 6 months or 12 months if neurodegenerative.<sup>112</sup> Participants raised several issues relating to assessing prognosis.

- Difficulty of prognostication

First, participants observed the difficulty of prognostication, particularly for patients who do not have a clear disease trajectory. Participants noted that prognostication was very much an art not a science, and it can be hard to do with any level of certainty.<sup>113</sup> Participants identified prognostication was challenging for conditions such as chronic obstructive pulmonary disease and neurodegenerative diseases. Challenges in prognostication were compounded for conditions where it was difficult to find a specialist (due to prevalence of conscientious objection amongst some specialities or due to appointment availability).



*Prognosis is a ... nightmare to determine ... particularly with patients with neurodegenerative conditions that don't have a clear trajectory. The practitioners struggle with it, particularly when they're not specialists in the area. [Participant 3]*

- Time period too short

Participants identified that the presence of a time-based prognosis requirement of 6 or 12 months (in the case of neurodegenerative diseases) created challenges in practice.<sup>114</sup> Uncertainties in relation to prognosis, or prognoses that were outside the prescribed window, often meant that patients needed to sustain further suffering for an arbitrary period of time, which seemed to undermine the guiding principles of the Act.

Some participants also observed that, in many cases, patients would experience anticipatory forms of suffering for the later stages of their disease, and by the time they reached that level of undesired deterioration they would be ineligible for VAD. It was noted that the ability of patients to be able to access VAD in a timely manner, before their health significantly deteriorated, would provide them with great comfort and would mean they could enjoy the final weeks of life, rather than enduring further stress through the assessment process.



*I think sometimes it leaves the patient feeling that they have to wait to get to a point in their health that they're trying to avoid in accessing VAD. They have to wait till they're that severely deteriorated in a position they didn't want to be. Which is really distressing for all of us. We can really see they're unwell, but the prognosis is just not supporting. [Participant 4]*

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<sup>112</sup> *Voluntary Assisted Dying Act 2019* (WA) s 16(1)(c)(ii).

<sup>113</sup> Challenges with prognosticating for the purposes of a VAD assessment have been observed elsewhere. For instance, in the WA VAD Board's Quality Practice Series the difficulties with existing clinical tools such as SPICT (Supportive and Palliative Care Indicators Tool) and Gold Standard's Framework PIG (Proactive Identification Guidance) were noted. Such tools have been developed to identify people who would benefit from end-of-life care planning, rather than provide a specific timeframe to death: WA VAD Board, *Quality Practice Series #5* (Western Australian Government: Department of Health, June 2023) <<https://www.health.wa.gov.au/~/-/media/Corp/Documents/Health-for/Voluntary-assisted-dying/VADBoardQualityPracticeSeries5.pdf>> (*Quality Practice Series #5*) 1. For further observations about difficulties of assessing prognosis for the purposes of a VAD assessment and the current prognostication timeframes see Rutherford, Willmott and White, n 26, 1071; Sellars et al, n 99, 4; *Conference Report: VAD CON 2023*, n 23, 8; *National VAD Survey*, n 23; *Victorian VADRB Report July 2022-June 2023*, n 26, 28-9; *Go Gentle Australia*, "There Could Not be a Truer Love", n 15.

<sup>114</sup> For similar observations, see Rutherford, Willmott and White, n 26, 1071; Sellars et al, n 99, 4.

Participants reflected that the ability for patients to access VAD before they severely deteriorated would likely decrease the likelihood of a patient missing out on accessing VAD and could alleviate some of the pressure on clinicians and the SWPS when presented with urgent cases. Having a more permissive prognostication window such as 12 months for all diseases, removing the prognostication window entirely and changing the criterion to something such as foreseeable death, or permitting an exemption were identified by participants as possible solutions.<sup>115</sup>

- Variability in approach

Concerns were also raised about the variability amongst practitioners with respect to their approach to prognostication. Some participants noted there was a lack of standardisation in terms of how eligibility was assessed amongst practitioners. For instance, participants observed that there appears to be uncertainty and divergent views amongst the medical community about whether a patient's decision to stop treatment or nutrition should be accounted for when making a prognosis.<sup>116</sup> The variability of approaches amongst practitioners was perceived to create a type of lottery in the sense that a patient's ability to access VAD was contingent upon which doctor was assessing them for VAD.

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*I have concerns around some of the standardisation across the state. We've started talking about it from a [health service provider] level that we do things very differently. But even just from a practitioner standpoint around prognosis and some of those aspects. That different practitioners have very different understandings of the legislation and the Guidelines, and that actually comes out in the way that they do their work. [Participant 6]*

Despite this, some participants indicated that variability in approaches to assessing patients was inevitable in medicine, and overall, there did appear to be concordance between coordinating and consulting assessments. There was also suggestion that this indicated that the eligibility criteria were being applied consistently.

- Referrals within a small pool of assessing practitioners

One participant opined that VAD practitioners, particularly within a health service setting, tended to refer between the same pool of VAD practitioners who tended to think the same way and approached VAD assessments similarly.<sup>117</sup> However, while this could be perceived as a risk, due to the small pool of VAD practitioners, this was also thought to be necessary.

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*We tend to refer between one another ... That's a good thing in a way because we're all like-minded professionals. But there is a thought that that could be perceived as an element of risk in that we're all like the same sort of person, think about it the same way ... always referring patients only between one another ... because there's a very small pool of practitioners and because mostly, I practice within a hospital setting. [Participant 33]*

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115 For the purposes of comparison, the Australian Capital Territory's new law will not have a prognosis limit and Queensland's law provides a prognosis limit of 12 months for all diseases. See *Voluntary Assisted Dying Act 2024* (ACT) s 11 and *Voluntary Assisted Dying Act 2021* (Qld) s 10(1)(a)(ii).

116 This scenario was identified by the *Quality Practice Series #5*, n 113, 1.

117 Concerns about referring between the small pool of VAD providers has previously been raised see Haining, Willmott and White, n 10.

## Citizenship

Under the WA VAD Act, a person accessing VAD must be an Australian citizen or permanent resident. Participants identified two concerns about this eligibility criterion. First, as evidenced by the literature, from a legal and practical perspective there are challenges in determining whether a person is an Australian citizen or permanent resident.<sup>118</sup> Participants echoed the practical challenges associated with a determination and noted the limited guidance to support practitioners on this issue.

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*Citizenship is incredibly difficult. There's no recourse for people to have a decision reviewed in that space ... There's no guidance for the practitioners in that space. They are essentially required to be immigration lawyers in many cases which is incredibly difficult. I never want to know anything else about Special Class Visas. It's a bloody nightmare. There's no support for the practitioners ... when they make that determination ... We've had doctors write to the Department of Home Affairs trying to clarify things and still none the wiser. [Participant 3]*

The second concern was that some individuals who had been living in WA for an extended time could not satisfy this criterion. One participant suggested that the current citizenship requirements raised concerns from an equity point of view, noting that the WA community was very diverse, and some members of the community who were on different Visa categories and had different residential statuses would not satisfy the criterion.

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*Not all people have the same access and equity in terms of Visa categories and residential status ... because we're a migrant settler society our Visa categories are so complex. We haven't actually dealt with any of those cases, but I wouldn't want those [people] to be ignored because there are people who've been here just as long and are still waiting for Visas or recognition ... it's not just the Ten Pound Poms, it's other people as well. [Participant 25]*

These sentiments are consistent with those of the WA VAD Board which has previously recommended expanding “access to [VAD] for long-term Australian residents who are not an Australian citizen or permanent resident”.<sup>119</sup>

## Residency

Under the WA VAD Act, a person must be ordinarily resident in WA for at least 12 months to be eligible to make a first request for VAD. Many participants criticised this requirement, and suggested it was somewhat redundant now that every state has legalised VAD. Recognising the mobility of the Australian population, participants observed there would always be cases where individuals would live in other states for certain periods, and that depriving VAD on that basis was unnecessarily limiting.<sup>120</sup>

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118 K Del Villar, L Willmott and BP White, “The Exclusion of Long-Term Australian Residents from Access to Voluntary Assisted Dying: A Critique of the ‘Permanent Resident’ Eligibility Criterion” (2023) 49(2) *Monash Law Review* 1; Willmott et al, “Participating Doctors’ Perspectives on the Regulation of Voluntary Assisted Dying in Victoria: A Qualitative Study”, n 26, 127; *Victorian VADRB Report July – December 2020*, n 99, 15; *Victorian VADRB Report July 2021-June 2022*, n 26, 31; *Victorian VADRB Report July 2022- June 2023*, n 26, 32.

119 *WA VADB 2022-2023 Report*, n 13, 55.

120 For critique on residency requirements which feature in Australian VAD laws see, for example, K Del Villar and Amelia Simpson, “Voluntary Assisted Dying for (Some) Residents Only: Have States Infringed S 117 of the Constitution?” (2022) 45(3) *Melbourne University Law Review* (advance); Hunt, n 33, 209; Waller, n 74, 1435.

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*Now that VAD is across Australia, or soon will be when the territories come on board ... we've got to have consideration around not only the fluidity of the assessments across the states, but also we've had reports where family members who have gone through a process in other states want to come spend their last few days with their family members in WA and vice versa, and it seems to me that we can facilitate that better. [Participant 24]*

Participants identified practical difficulties in assessing the residency requirements.<sup>121</sup> However, the recent series of Western Australian State Administrative Tribunal (WASAT) decisions<sup>122</sup> were thought to be positive in terms of giving further guidance to practitioners. Participants spoke favourably of the WASAT, and the fact that VAD cases were being considered by the Tribunal on an urgent basis. However, they also noted that WASAT ultimately had limited jurisdiction which was interpreting the existing criterion of “ordinarily resident”. Participants expressed a desire for a more flexible approach and suggested that individuals should be able to be granted a residency exemption (as is available in some other jurisdictions), if there were a sufficient connection to WA.<sup>123</sup> The WA Board has also previously called for “an exemption pathway” in relation to the residency requirements.<sup>124</sup>

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*We've had quite a few patients who have got residency and have travelled and moved interstate. And that really has become an issue. I believe other states have put something where at least they have a tribunal where it can be appealed. Whereas we can question the definition, but we can't appeal it. Even if the criteria didn't change but there was some capacity for appeal. [Participant 19]*

### Disease expected to cause death

Under the WA VAD Act, a person is required to have “at least [one] disease, illness, or medical condition”.<sup>125</sup> Participants identified that, in practice, the framing of this criterion could create challenges. Cases that were especially challenging for practitioners were patients who did not have a single condition expected to cause death but were frail and had a combination of co-morbidities and were likely to die within the necessary timeframe. Such scenarios were perceived to lead to a degree of uncertainty for doctors and place them at medicolegal risk if they did not document the ‘right disease’ for reporting and documentation purposes. Risk was felt to be greater for medical practitioners working within multidisciplinary settings (such as a health service or aged care facility) who were perceived to be under constant scrutiny.

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121 Difficulties in assessing residency and gathering the necessary evidence to make such an assessment has been observed elsewhere see Willmott et al, “Participating Doctors’ Perspectives on the Regulation of Voluntary Assisted Dying in Victoria: A Qualitative Study”, n 26,127; *Victorian VADRB Report June 2019 – December 2019*, n 99, 7; *Victorian VADRB January 2020- June 2020*, n 69, 8; *Victorian VADRB Report July – December 2020*, n 99, 15.

122 *AB and CD* [2024] WASAT 6; *BMR, MTH and CJG and the Co-ordinating Practitioner for MTH* [2024] WASAT 44; *EF, GH AND IJ and KL* [2024] WASAT 18; *HM and the Co-ordinating Practitioner for HM* [2024] WASAT 23. See also K Bourke, “Can You Still Access Voluntary Assisted Dying Laws if You've Been Living Elsewhere for a Decade Or More?”, *ABC News*, 24 April 2024 <<https://www.abc.net.au/news/2024-04-24/is-vad-in-wa-open-to-you-if-you-have-been-living-overseas/103655686>>; R Peppiatt, “WA Man Fights for Right to ‘Die with Dignity’ in First-of-its-kind SAT Hearing”, *WA Today*, 21 February 2024 <<https://www.watoday.com.au/national/western-australia/wa-man-fights-for-right-to-die-with-dignity-in-first-of-its-kind-sat-hearing-20240216-p5f5n0.html>>.

123 For comparative purposes see *Voluntary Assisted Dying Act 2021* (Qld) s 12; *Voluntary Assisted Dying Act 2022* (NSW) s 17; *Voluntary Assisted Dying Act 2024* (ACT) ss 11(1)(f)(i),154.

124 The WA VADB recommended the WA VAD Act be amended to “provide an exemption pathway to the ordinary residency requirements for people who have a substantial connection to [WA] or have been found eligible in another Australian jurisdiction”. See *WA VADB 2022-2023 Report*, n 13, 55.

125 *Voluntary Assisted Dying Act 2019* (WA) s 16(1)(c).



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*We ... very often have patients present with an unrecognised diagnosis of frailty in our country. You're pulling all the co-morbidities together. Everybody knows that this person is dying. They're referred to palliative care. Sometimes they're planned to go to a hospice, but they don't have a thing that somebody can pin it on. [Participant 5]*

## Capacity

Under the WA VAD Act, a person is required to have decision-making capacity throughout the process. While assessing capacity was unproblematic in many cases, there were circumstances which proved challenging. For instance, one area of challenge identified was the impact of a Guardianship Order on a capacity assessment.<sup>126</sup> Participants also identified challenges, and expressed a degree of frustration, with respect to cases where a patient may have decision-making capacity at the time of an eligibility assessment, but subsequently lose capacity before completing the process, rendering them no longer eligible for VAD. This could happen for a range of reasons including from medical treatment received to manage pain or other symptoms.

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*So, we have had a report where a participant of VAD, his plan was to undertake VAD, but he deteriorated quite rapidly ... And then his medical needs were such that he was sedated past the point where he could give consent to his VAD administration ... So, for him, his death was prolonged, and that wasn't what his wishes were. [Participant 9]*

There was also evidence of patients who were so concerned about the effect of pain-relieving medication on their decision-making capacity (and hence their ability to access VAD), that they opted to scale back opioid analgesic medications.<sup>127</sup>

Many participants across a range of stakeholder groups talked about dementia and the inability of a person to receive VAD on the basis of this condition alone. Some participants have suggested that some form of advanced consent (such as through an advance health directive)<sup>128</sup> could be a potential option. However, there was ambivalence about whether VAD should be extended to dementia patients and, if so, how this would be best regulated.<sup>129</sup> Regardless of the position taken, however, participants suggested that this is an issue that cannot be ignored and there is a need for further consideration, discussion and research.

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126 The authors note this was a previous area of focus in the Quality Practice Series see WA VAD Board, *Quality Practice Series #7* (Western Australian Government: Department of Health, December 2023) <<https://www.health.wa.gov.au/~media/Corp/Documents/Health-for/Voluntary-assisted-dying/VADBoardQualityPracticeSeries5.pdf>> 2.

127 This has similarly been reported elsewhere see Go Gentle Australia, "'We've Seen Gentle, Beautiful Deaths'", n 15.

128 Under current WA laws VAD cannot be formally consented to via an advance health directive see *Guardianship and Administration Act 1990* (WA) s 3B. This is not to suggest that VAD cannot be discussed during advance care planning see BP White et al, "Implications of Voluntary Assisted Dying for Advance Care Planning" (2024) 220(3) *Medical Journal of Australia* 129.

129 Mixed views on this issue have also been reported elsewhere see, for example, Hunt, n 33; PA Komesaroff et al, "Should Voluntary Assisted Dying in Victoria be Extended to Encompass People with Dementia?" (2024) 220(9) *Medical Journal of Australia* 452; Sellars et al, n 99, 4; *National VAD Survey*, n 23; Bourke, n 122; Cath News, "WA Review Rules out Euthanasia for People With Dementia", 28 November 2023 <<https://cathnews.com/2023/11/28/wa-review-rules-out-euthanasia-for-people-with-dementia/>>; R Le May, "Roger Cook Flags Expanding Voluntary Assisted Dying Laws to Dementia Patients, Leaves Door Open to Teens", *The West Australian*, 2 August 2023 <<https://thewest.com.au/politics/state-politics/roger-cook-flags-expanding-voluntary-assisted-dying-laws-to-dementia-patients-leaves-door-open-to-teens-c-11462717>>; Peppiatt, n 122; BP White et al, "People with Dementia Aren't Currently Eligible for Voluntary Assisted Dying. Should They Be?", *The Conversation*, 21 May 2024 <<https://theconversation.com/people-with-dementia-arent-currently-eligible-for-voluntary-assisted-dying-should-they-be-224075>>; T Wong-See, "Husband Calls for Voluntary Assisted Dying Access For WA Dementia Patients After Wife's Tragic Death", *ABC Great Southern*, 22 August 2023 <<https://www.abc.net.au/news/2023-08-22/calls-for-voluntary-assisted-dying-access-dementia-patients-wa/102755336>>; Zimmerman, "Voluntary Assisted Dying: Mark McGowan Supports Dementia Sufferers Accessing VAD And Larger Telehealth Role", n 99.



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*Dementia is – and the fear of it – is what everyone raises with us all the time ... it is the big-ticket item. It's not easily addressed, but we need to engage in that discussion. [Participant 13]*

### Voluntary and enduring request

Under the WA VAD Act, to be eligible for VAD a person must be acting voluntarily and without coercion, and the person's request for accessing VAD must be enduring.<sup>130</sup> Participants did not indicate that these two eligibility criteria posed any significant issues in practice. In fact, participants observed that coercion tends to operate the other way, where people (including the patient's loved ones and treating teams) tried to coerce people out of accessing VAD.<sup>131</sup>

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*There [were] concerns about coercion towards VAD. We probably see more of that negative coercion. People being either not offered it as an option or being told that they have still plenty of options available. [Participant 11]*

One way the enduring nature of the request is tested is through the mandatory waiting period. Ordinarily there must be a nine day period from the first request until the final request, and one day from the consulting assessment until the final request.<sup>132</sup> The intention behind the provision was to ensure that the process is not rushed and to give people enough time to consider all information and contemplate the effect of their decision.<sup>133</sup> The process can be expedited if the patient is likely to die or lose decision-making capacity before the end of the designated period.<sup>134</sup>

Participants reported that the waiting period presented some practical challenges. While understanding that the policy intent behind the waiting period was to ensure that the person's request for VAD was enduring, participants noted that in many cases individuals had been seeking VAD for a long period but, for reasons beyond their control, the first request was only recently made. In such a case, some practitioners regarded the nine day waiting period to be punitive. Some also expressed concern that expediting the period exposed practitioners to some kind of medicolegal risk.

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*There needs to be agreement between the two practitioners ... about the risk of somebody dying or losing capacity. [This] feels a little bit, or sometimes a lot, punitive in terms of the patient who may have been requesting this for months and not been responded to. We're now saying, "Now that we've heard your request, you still have to wait effectively at least a week and a half when you've already waited two months and you've been asking people all over the place" ... I think we're much more experienced by and large, particularly those experienced practitioners, in determining that somebody clearly has an enduring request. We don't need to test that for nine days. [The current process] puts practitioners in a place of medicolegal vulnerability, for them to agree on expediting a process by finding the possibility of something, just to make it happen. [Participant 5]*

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130 *Voluntary Assisted Dying Act 2019* (WA) s 16(1)(e)-(f).

131 W John, *The Human Reality of Helping a Patient Die* (The Medical Republic, 25 January 2023) <<https://www.medicalrepublic.com.au/the-human-reality-of-helping-a-patient-die/16527>>.

132 *Voluntary Assisted Dying Act 2019* (WA) s 48.

133 Explanatory Memorandum *Voluntary Assisted Dying Bill 2019* cl 47.

134 *Voluntary Assisted Dying Act 2019* (WA) s 48(3).

### *Issues identified*

Given eligibility criteria for VAD are outside this current Review, the authors did not specifically seek input on this issue in the interviews and focus groups specifically conducted for the purpose of the Review. Nevertheless, participants made a range of comments about the appropriateness of the existing eligibility criteria and the lack of mechanism for an individual seeking VAD to apply for an exemption. Participants also raised practical challenges in applying the current eligibility criteria, and expressed concerns about the uncertainties surrounding prognostication and the lack of guidance where there was legislative silence (e.g. in cases where patients had the VAD substance dispensed but then lost decision-making capacity). The current timeframe of 6 or 12 months until death was repeatedly identified as challenging for practitioners as well as for their patients (e.g. due to the potential need for patients to endure additional suffering). Participants also identified that the issue of whether VAD should be available to those with dementia was an area that needed further examination.

### *Recommended responses*

The authors consider there is merit to many of the issues raised by the participants. With respect to the challenges associated with applying current eligibility criteria (e.g. due to legislative silence or current uncertainties with respect to certain clinical presentations), the DoH or WA VAD Board should consider whether further support or guidance may be beneficial for VAD practitioners. This could occur, for example, through further guidance, educational sessions, the Quality Practice Series, the information hub on the VAD-IMS, or discussions in the Community of Practice.

With respect to the nature of the current eligibility criteria, although they are outside the scope of this Review, it would be prudent for these issues to be examined in future reviews. Some of these issues were debated extensively at the time of passing the WA law. However, some of the issues raised should be reassessed in light of growing evidence of how VAD is operating in WA and other Australian states (as well as drawing on international evidence, where relevant), in addition to current community views. In particular, given the frequency with which they were raised by participants, the current prognostication timeframes and potential access of individuals with dementia should be considered in subsequent reviews.

## **Recommendation 10**

**Future reviews of the WA VAD Act should consider current eligibility criteria for VAD.**

# Chapter 4: Prescription, administration, disposal and post-death

This chapter considers the processes that occur for the patient (and their loved ones) after the patient has been assessed as eligible for VAD and the VAD substance has been prescribed. It considers the prescription delivery process, the transportation of the VAD substance, the administration process, and the disposal of the VAD substance. It also considers after death components including the role of the contact person, certification of death and grief and bereavement supports.

## 4.1 Prescription delivery

Under section 70(6) of the WA VAD Act, “the coordinating practitioner must give the prescription directly to an authorised supplier”.<sup>135</sup> In practice, this requirement has been interpreted narrowly to mean that only the practitioner can deliver the prescription directly (or do so via registered post or an authorised courier) to the SWPS (the authorised supplier).<sup>136</sup> As a consequence, in practice, other personnel who may be well-placed to deliver the prescription (such as the SWCNS, institutional VAD Coordinators or pharmacy technicians) are unable to pick up the prescription from the VAD practitioner and deliver it to the SWPS. This was also an area that the WA VAD Board has recommended to be reformed.<sup>137</sup>

### *Participants’ submissions and evidence*

Participants perceived section 70(6), and the way in which it has been interpreted, placed unfair burdens on VAD practitioners in terms of time and associated cost to either travel to the pharmacy or organise a courier service or postage. In addition, it was observed that such steps inevitably resulted in delays. Participants observed that such practices were practically unnecessary as, on occasions, personnel from the SWCNS or institutional VAD Coordinators had been available to deliver the script. It was also noted that while pharmacists from the SWPS had sometimes driven out to collect scripts from medical practitioners in an attempt to save them time, this was also unnecessarily creating burdens on the SWPS.

*Accessibility ... as far as having it available ... especially regional areas again [and just] getting script to pharmacy and the barriers to that and that having to be the practitioner themselves, or a courier or post ... so [practitioners] have to organise a courier sometimes from five hours away, when [the Care Navigator is] right there with the practitioner and could actually bring up the script to Perth to give the pharmacy. So that causes definite delays. [Participant 4]*

*A rando courier or Australia Post is fine, but the people that are walking through the process and employed to do the role are not OK to be hand-delivering a sensitive document. [Participant 5]*

135 Voluntary Assisted Dying Act 2019 (WA) s 70(6).

136 WA VAD Guidelines, n 49, 58.

137 WA VADB 2022-2023 Report, n 13, 55.

Participants also considered that the inability to use electronic prescriptions was unnecessarily limiting. While it was identified that the Commonwealth Criminal Code currently precluded the use of electronic prescriptions, participants emphasised that even if the law were changed, the current legal framework would not support electronic prescriptions. Multiple participants expressed desire for some form of electronic prescribing infrastructure, with different models proposed, including the use of digital image prescriptions.<sup>138</sup>

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*The WA legislation is not set up to cater for an environment for us to do electronic prescribing tomorrow. Let's say [the Commonwealth Criminal Code changes], we're not ready to go.*

[Participant 10]

### *Issues identified*

As section 70(6) in the WA VAD Act is currently interpreted, there are limited avenues for the coordinating practitioner to deliver the prescription to the authorised supplier. The current practice imposes unnecessary and unfair burdens on VAD practitioners. These unnecessary logistical barriers also create barriers for patients accessing VAD, particularly patients living regionally.

The authors note that the WA VAD Act currently allows an “agent” to collect and deliver the actual VAD substance.<sup>139</sup> Logically, it is not justifiable to more tightly control delivery of a prescription.

### *Recommended responses*

The category of individuals permitted to transport the prescription from the coordinating practitioner to the authorised supplier should be broadened. Staff from the SWCNS, VAD Coordinators and SWPS technicians would all be suitable for this task and allowing them to do so would not affect the safety of the process.

This issue could be addressed by amending the WA VAD Act to explicitly authorise delivery of the prescription by a broader category of individuals. An alternative strategy is that the DoH could revisit the current narrow interpretation of the legislation in the WA VAD Guidelines. A broader interpretation of section 70(6) may be more consistent with some of the guiding principles of the WA VAD Act and the Government’s commitments to facilitating access, including those set out in the Access Standard.<sup>140</sup>

## **Recommendation 11**

**Broaden the category of individuals who are authorised to deliver a prescription to an authorised supplier.**

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138 An example of instrument that permitted digital image prescriptions temporarily during the COVID-19 pandemic is *Authorisation (No 6) to Supply or Prescribe a Poison* (WA) <[https://www.wa.gov.au/system/files/2021-12/Authorisation\\_No\\_6\\_to\\_Supply\\_or\\_Prescribe\\_a\\_Poison.pdf](https://www.wa.gov.au/system/files/2021-12/Authorisation_No_6_to_Supply_or_Prescribe_a_Poison.pdf)>. This instrument was made pursuant to the *Public Health Act 2016* (WA) and is no longer in force. The WA VAD Board has also shown support for use of electronic prescribing in relation to VAD see *WA VADB 2022-2023 Report*, n 13, 55.

139 *Voluntary Assisted Dying Act 2019* (WA) s 58.

140 *Access Standard*, n 29, 2.

## 4.2 Transporting substance

The WA VAD Act currently prohibits any person apart from the patient from transporting the VAD substance once it has been supplied to the patient. The agent or contact person can only possess the substance for the purposes of supplying it to the patient.<sup>141</sup> This creates difficulty in cases where a patient transitions between care settings (e.g. between a residential aged care facility and a hospital). The current framing of the law precludes another person from bringing the substance to the patient in the new facility.

Participants believed the current restrictions on transporting the VAD substance put people at unnecessary medicolegal risk. Participants suggested that the patient's loved ones, in practice, would on occasion transport the substance to the patient's new care location (hence contravening the law). Alternatively, the patient may be encouraged to take the substance with them whenever they travel to a new care setting, which was believed to create undesirable risks.

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*There's a bit of an issue [in] when [the medication is supplied] to a patient, the patient is the person who is now in possession of the VAD substance and no one else can be in possession of it. If the patient then goes to hospital and they didn't take the kit, which we really don't want them taking the kit just because they're going in for something non-life threatening, but then they decide they want the VAD substance kit, in theory, no one can bring it to them because no one else is allowed to be in possession of it. I think that is something that needs to be written into the law.*  
[Participant 11]

### *Issues identified*

Lack of legal authority for someone, other than the patient, to transfer the VAD substance between care settings has undesirable outcomes: the patient may not be able to access the VAD substance in the new care setting, as they desire; or the patient may need to transport the VAD substance wherever they go, creating unnecessary medication safety risk.

### *Recommended responses*

A person should be allowed to transport the VAD substance across care settings on behalf of a patient. Amending the WA VAD Act to explicitly authorise a person to transfer the VAD substance on the patient's behalf would be the most effective and appropriate solution. Failure to do so would put that person at legal risk.

Until legislative amendment can occur, patients should be encouraged to take the VAD substance with them when they transition across care settings if they believe they may wish to use it at the new location. To promote safety, entities should also ensure that a safe place to store the VAD substance is available upon transfer.

## **Recommendation 12**

**When a patient transitions between care settings, facilitate the transport of the VAD substance to the new care setting by another person authorised by the patient to do so.**

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141 Voluntary Assisted Dying Act 2019 (WA) ss 58(7), 67(1).

### 4.3 Administration

Under the WA VAD Act, administration can occur via self-administration or practitioner administration. Patients are required to make an administration decision with, and on the advice of, their coordinating practitioner.<sup>142</sup> If the original administration decision is no longer appropriate, the patient must formally revoke the administration decision and make a new decision.<sup>143</sup> In cases of self-administration there is no requirement for a health practitioner to be present. However, often in practice, a VAD practitioner and/or a member from the SWCNS or VAD Coordinator would be present for administration to support the patient, their loved ones and the administering practitioner.

#### *Participants' submissions and evidence*

- Proportion of practitioner administration

One surprising feature of the WA system has been the high proportion of practitioner-administered deaths compared to self-administration.<sup>144</sup> Some participants suggested that the manner in which VAD practitioners approached administration decision conversations may have contributed to this. Indeed, some participants suggested that some VAD practitioners conveyed (even if unintentionally) a preference for practitioner administration, which was thought to influence patients' decisions.

To further promote informed patient choice, some participants suggested it would be useful to develop resources setting out the advantages and disadvantages of each administration option. It was noted that currently practitioners are required only to provide written information on the administration route that is chosen.<sup>145</sup>

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*I think you want a lot of patient ability to make that decision. I think that's got to be the key message. You really want some sort of informed consent, for want of a better word, process in terms of pros and cons to go through it ... I do think our practitioners overly push the practitioner admin because that's just become part of the culture. [Participant 10]*

*[During] the admin decision the practitioner must give written information but it's on the route that's chosen; it's not necessarily on all the options. [Participant 11]*

Participants suggested some patients were opting for IV administration, due to reservations about the bitterness of the VAD substance or because they perceived that IV deaths were quicker and offered greater certainty. Participants also suggested that some patients opt for practitioner administration (or at least practitioner presence) due to a desire for continuity of support.

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*[It's] understood that the medication's very bitter and there's a worry about vomiting and not being able to go through the process I suppose. And we've also speculated that perhaps there's a comfort that there's a medical practitioner present. So, if you're getting practitioner assistance, well there's a doctor there, at least one medical practitioner there plus or minus a nurse, to help with the aftermath of the death. [Participant 26]*

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<sup>142</sup> Voluntary Assisted Dying Act 2019 (WA) s 56.

<sup>143</sup> Voluntary Assisted Dying Act 2019 (WA) s 57.

<sup>144</sup> Go Gentle Australia, "It's a New System and There Are Still Some Challenges", 13 December 2022 <[https://www.gogentleaustralia.org.au/dr\\_sarah\\_pickstock\\_is\\_a\\_palliative\\_care\\_specialist\\_and\\_voluntary\\_assisted\\_dying\\_practitioner](https://www.gogentleaustralia.org.au/dr_sarah_pickstock_is_a_palliative_care_specialist_and_voluntary_assisted_dying_practitioner)>.

<sup>145</sup> Voluntary Assisted Dying Act 2019 (WA) s 69.

- Prohibition on assisting person to self-administer

Participants frequently discussed the current prohibition on assisting the patient to prepare the VAD substance. Amongst participants there was speculation about whether this influences patients to choose practitioner administration. The authors note that this prohibition has previously been identified as an issue of concern by the WA VAD Board.<sup>146</sup> Participants suggested the law should be reformed to permit such assistance, although views were mixed about whether that support should be available from family and friends.

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*The fact that no one else can help [patients] prepare them is challenging and I don't know that Victoria's legislation is necessarily correct either. I think when we entered into this, I thought it was really prohibitive that people couldn't have someone help support them prepare the medication. Now I'm not entirely sure that that would be a positive thing to have available in all cases. I think it puts a lot of pressure on family and support people to facilitate access to VAD ... But I would be very keen to see there be capacity for an appropriate health professional to support someone to do it, who doesn't have to be a doctor or a nurse practitioner who's done the training. So that the person and their family aren't alone. [Participant 3]*

- Simplifying process to change the administration decision

In cases where the original selected administration pathway is no longer appropriate for the patient, the current processes require the original decision to be revoked, a new prescription to be provided, and new kit dispensed. This inevitably results in delays. Participants described the process as burdensome and expressed a preference for a more streamlined approach. Some participants suggested permitting multiple kits to be dispensed and allowing practitioners to move between protocols if needed would be beneficial and would assist with streamlining. However, there were also reservations expressed in relation to dispensing multiple kits due to the associated wastage which would result from such an approach.

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*No capacity for multiple options to be dispensed ... is an acute care issue for patients. We've had a number of cases where IV access has not been obtainable where that was the person's wish but not a requirement ... so changing to oral administration revolves around a massive trip back to pharmacy ... Similarly, where a practitioner arrives to a patient with the intent of doing oral or feeding tube administration and then that's no longer possible. Then again, the same trip happens to get access to an intravenous option. It's incredibly distressing for everyone. [Participant 3]*

*I know in other countries overseas that they sometimes take two kits. So, if something goes wrong, they've got another option. That's something practitioners have proposed but it would lead to a lot of wastage because [the SWPS] don't take medications back once they've left [their] site. [Participant 11]*

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<sup>146</sup> WA VADB 2021-2022 Report, n 13, 39. The barriers that are created by putting restrictions on others assisting to prepare the VAD substance in cases of self-administration have also been identified in previous research in WA see Haining, Willmott and White, n 4, 740-741.



- Simplify the process for transferring between administering practitioners

Participants also identified that the current process for transferring the administering role to another practitioner (whether a medical or a nurse practitioner) was unnecessarily complex. Participants reported that difficulties commonly arose when the coordinating practitioner was no longer available to administer (e.g. due to a lack of capacity or being on leave). In such cases, a new administering practitioner could be assigned. However, participants noted that the current processes can be administratively burdensome. Indeed, such cases required the originally assigned administering practitioner to log on to the VAD-IMS to facilitate the transfer. This was considered impractical and challenging at times, particularly in cases when they did not have access to the VAD-IMS when the transfer needed to occur. Similarly, due to the absence of a streamlined transfer process, participants described that difficulties also arose in cases when a transfer of administering practitioner was made (e.g. because the patient was expected to take the substance while the original administering practitioner was on leave) but circumstances changed and the original administering practitioner was now able to carry out the administration (e.g. because they returned from leave).

Participants expressed a preference to simplify and streamline this process. Participants suggested this could be achieved by permitting the nomination of multiple administering practitioners so if the originally intended administering practitioner is unavailable, one of the other listed administering practitioners could step in.



*When a practitioner is no longer available, usually they're on leave. You go on leave, your patients are stable. Do you transfer them to another practitioner? Transfer the medications? Because if you have the possession of the medications and you don't transfer them, the patient would have no option to administer until they return. If they had to go back to the start, they'd have to have a new administration decision made, a new coordinating practitioner allocated. It's a really big gap. If you transfer the patient to a new administering practitioner and you come back, and they didn't need it then you've got to transfer them back to yourself. [Participant 11]*

- Permitting practitioner administration for 'failed' administration

VAD deaths (particularly via the oral route) can vary from patient-to-patient.<sup>147</sup> Participants reflected on the issue of 'failed' administrations such as when there were longer than expected time intervals between administration and death due to the patient's medical condition (and inability to absorb the substance) or because a patient vomited some of the VAD substance. Such 'failures' were observed to be challenging for those present at the patient's death. Some participants suggested that consideration should be given to allowing an attending practitioner to provide practitioner IV administration, as is currently possible in Tasmania,<sup>148</sup> without the need to formally change the administration method.

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147 Sellars et al, n 99, 5.

148 *End of Life Choices (Voluntary Assisted Dying) Act 2021 (Tas)* s 88.

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*It took about four hours for him – four-and-a-quarter hours between drinking the substance and ... biologically just took a bit longer to get where it needed to go. But yes, it was an interesting experience to have it take that long. In hindsight, I think it was positive for myself to be able to say goodbye over that length of time. But my brother found it very difficult ... the doctor and the Care Navigator were there the entire time. And I'm eternally, eternally grateful for their presence.* [Participant 9]

*It would be great to have flexibility, wouldn't it, for the potential case ... of a self-administration where it goes wrong. It's not working. It's not getting the job done. Is the person throwing up or whatever? I don't know. And if a doctor is present – whether the consulting practitioner or another – should they not be permitted to intervene to really take it over and provide practitioner administration?* [Participant 13]

### *Issues identified*

Several issues associated with administration were identified by participants:

- the proportion of practitioner vs self-administered VAD deaths in WA;
- the inability to assist a patient prepare the VAD substance in cases of self-administration;
- the administrative complexities with changing the administration decision and changing administering practitioners; and
- difficulties associated with 'failed' administrations.

### *Recommended responses*

- The proportion of practitioner vs self-administered VAD deaths in WA

Informed decisions about methods of administration of VAD are needed to facilitate patient choice. Practitioners discussing administration decisions with patients should ensure that they are fully informed and aware of the relative merits of each option. The development of standardised resources that cover such content may help facilitate those discussions. Different proportions of administration methods have been observed by the WA VAD Board, and the DoH may wish to monitor trends over time.<sup>149</sup>

- The inability to assist a patient prepare the VAD substance in cases of self-administration

It is desirable for a patient to be permitted to receive assistance to prepare the VAD substance if this help is wanted. This is allowed in other jurisdictions and there is no evidence that this kind of assistance compromises the voluntariness of the patient's choice to take the VAD substance. This is best addressed by amendment to the WA VAD Act to permit this assistance. Pending legislative reform, the DoH should also consider whether alternative strategies may help address this issue such as clarifying what constitutes prohibited assistance and whether there are any steps that others may lawfully do which would not be considered preparation of a VAD substance.

- The administrative complexities around changing the administration decision and changing administering practitioners

Changing the administration decision and transferring to another administering practitioner are two processes that commonly occur during the VAD process, and there is a need to simplify both processes. Some of the current complexities are the product of how the legislation is framed in terms of the requirements for formal revocation, and restrictions placed on the number of administering practitioners that can be appointed. Legislative amendment would be the most effective way to address these complexities; however, changes to existing system design may also help streamline these processes and should also be considered.

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<sup>149</sup> WA VADB 2022-2023 Report, n 13, 33.

- Difficulties associated with ‘failed’ administrations

The authors recommend consideration be given in future reviews to permitting practitioner administration for ‘failed’ self-administrations (where a patient consents to this in advance). Although there is little evidence of complications of self-administration, evidence suggests that, when this occurs, it can be distressing for the patient’s loved ones.<sup>150</sup> Evidence from the Tasmanian experience (where this is permitted) should inform these future deliberations.

### **Recommendation 13**

**Allow assistance to be provided to the patient, if requested, to prepare their VAD substance.**

### **Recommendation 14**

**Simplify the process for changing the method of administration including in cases where self-administration is no longer appropriate.**

### **Recommendation 15**

**Simplify the process for transferring the role of administering practitioner.**

### **Recommendation 16**

**Future reviews should consider amending legislation to permit practitioner administration if self-administration ‘fails’.**

## **4.4 Storage and disposal**

Under the WA VAD Act, an authorised disposer can receive any unused or remaining VAD substance for the purposes of disposal. The Act requires disposal to occur “as soon as practicable after receiving it” but does not provide a specific time within which this should occur.<sup>151</sup> Clarity is also not provided in the DoH’s Guidelines. Upon disposal, the authorised disposer must immediately complete the Authorised Disposal Form and provide a copy to the VAD Board via the VAD-IMS within two business days of disposing of the substance.<sup>152</sup>

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150 Sellars et al, n 99, 5.

151 *Voluntary Assisted Dying Act 2019* (WA) s 75(3).

152 *Voluntary Assisted Dying Act 2019* (WA) ss 76(1), 76(3).

## Participants' submissions and evidence

- Lack of specific timeframe for disposal

Participants identified that the current lack of legislative clarity about explicit timeframes for disposal created practical difficulties. Participants reported that, on occasions, because of the lack of a specific timeframe, it had taken months for disposal to occur. The lack of timeframe has also made it hard to track the VAD substance. This meant, in some cases, it was not clear whether the substance was still with the contact person or had been given to the authorised disposer. On occasions, this has led to unnecessary follow up with the contact person.

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*An authorised disposer needs to dispose of the substance, I think it says something in it as soon as is practical. We've had that be months ... until the authorised disposer does the disposal, it still looks like the kit sits with the contact person. The VAD Board may be calling the contact person saying, "Why haven't you taken it to a Pharmacy yet?" But they may have done. The pharmacy's just sitting there and haven't done anything with it. It's a bit of a loophole which potentially puts the contact person in an awkward position. [Participant 11]*

- Storage and disposal of residual VAD substance

Administering practitioners will collect the VAD substance prior to administration (sometimes well in advance). Additionally, in some cases, the administering practitioner may have residual VAD substance in their possession following patient administration. Some participants raised concerns about both of these stages.

Firstly, it was noted that VAD practitioners would sometimes keep the VAD substance at their premises prior to a scheduled administration. Participants observed that this was not consistent with good practice for medication storage.

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*It's working OK it's just ... [there are occasions where the SWPS] may be supplying to a practitioner living in a shared house. Where [are they] meant to store it? We are putting a bit of onus back on those practitioners to manage and own that. They may end up with multiple four, five kits stored in their house. It's really not the intention and not good storage practice. [Participant 11]*

Secondly, concerns were raised about aspects of disposal practices. Some suggested that the disposal process may be more uniform (and safer) if legislation required practitioner disposal to be witnessed. Practical barriers to such a requirement, however, were also noted. Participants also identified that the current framing of the WA VAD Act puts practitioners at medicolegal risk in some circumstances, which has also previously been identified by the Board.<sup>153</sup> Currently, section 77 of the WA VAD Act only permits the administering practitioner to possess and dispose of the VAD substance in cases where the patient has revoked the practitioner administration decision or if the patient has died (whether or not from the VAD substance). This means that in cases that a patient no longer meets the eligibility criteria (e.g. loses capacity), the legislation does not provide authorisation for the practitioner to lawfully possess and dispose the VAD substance.

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153 WA VADB 2021-2022 Report, n 13, 38.

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*I think there's a few practitioners who feel a bit uncomfortable that any disposal isn't witnessed so that's just up to them. But it's a bit of an awkward one that you might be out in the middle of nowhere. [Participant 11]*

*To have all this [medication] sitting around that they then are supposed to dispose of distresses them. And while I sort of say that I think that they are careful not to leave anything behind that could be misused by other people, I have to say that it doesn't all get back to the disposer. Probably a lot of it goes down the sink. I mean why would you track it all back to the disposer? I mean it's just ridiculous. [Participant 13]*

*The legislation is flawed in relation to the disposal and possession of substance. So, it needs to be changed. Because if a practitioner rocks up to see a patient and they've got the kit with them and they are unable to do their administration because the person's lost capacity, that practitioner [is] not authorised to possess the substance for the purpose of disposal. [Participant 19]*

### *Issues identified*

Community safety requires sound systems to manage safe custody and disposal of VAD substances. Two main issues were identified in relation to current practice. The first was the lack of timeframe within which an authorised disposer must dispose of the substance. It is preferable for a disposer to have clarity about their obligations. Also, a lack of timeframe for disposal makes it difficult to track where the substance might be and can lead to unnecessarily reaching out to the contact person.

The second issue is the potential medicolegal risk for administering practitioners who are in possession of the VAD substance in the absence of express legal authority.

### *Recommended responses*

These issues are most effectively addressed by legislative amendment to the WA VAD Act. The Act could impose a timeframe in which an authorised disposer should dispose of the substance and provide legal authority for an administering practitioner to possess the VAD substance if the patient is no longer eligible. However, non-legislative responses may also assist in addressing these issues and should be explored. One option is for current disposal forms (which are approved by the CEO) to recognise additional reasons for disposal or specify a timeframe within which disposal can occur. Another option is to provide further guidance (e.g. in the VAD Guidelines).

## **Recommendation 17**

**Make changes to legislation, forms, and/or current guidance to:**

- **establish or advise on a specific timeframe for the authorised disposal to occur; and**
- **permit the administering practitioner to possess and dispose of the VAD substance to accommodate all cases where the practitioner is appropriately in possession of the substance.**

## 4.5 Grief and bereavement

Participants described that people found journeying with and supporting someone through the VAD process to be a largely positive experience. However, it was generally acknowledged by participants that this process can be emotionally challenging for people, even if they morally supported the person's choice to access VAD. The WA VAD Board in its most recent report identified the need for more VAD-specific grief and bereavement resources, practitioner guidance and referral pathways.<sup>154</sup>

### *Participants' submissions and evidence*

Participants identified that there are some aspects of the VAD grief and bereavement experience that are different from non-VAD deaths.<sup>155</sup> While some people were heartened by the VAD process and death and took pride that their loved one could end their life on their own terms, they still reported experiencing complex forms of grief. Grief experiences were variable and included anticipatory grief, forms of complicity grief associated with supporting a patient through a process that ultimately resulted in death, and feeling guilty and unsettled by the fact that they have coped well with their loved ones' death. Participants reported that some people found the uniqueness of the VAD grief isolating. Grief was not only experienced by the patient's loved ones, but also some of personnel directly involved in the person's VAD care, as well as those related to other aspects of the patients' care (such as community nursing staff and interpreters).

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*[I] found it very isolating. You don't know people who have gone through this journey. It's an incredibly confronting thing to be knowing that you've got a ticking clock waiting for that loved one to die. Even though it's what they want and you're supporting them very much with their wishes, it's just something that the human condition isn't ... we're primed to keep people alive and to support people. [Participant 9]*

*What people, particularly in the palliative care space, have found is that it is a bit different ... people ... because of their work, they really don't have issues with people dying in the service. They have found that they have had some issues when the person that you're looking after essentially farewells you because they then say, "Well, I'm dying tomorrow because that's when I'm going to take the substance", and people have found that really confronting in ways that they didn't even expect. [Participant 38]*

Participants largely felt that VAD-specific grief and bereavement services were under resourced, and while general grief and bereavement services were available, they were often not appropriate or tailored to meet people's needs. Participants suggested some people might be reluctant to engage general bereavement supports due to uncertainty about how a VAD death might be judged. The need to engage with people unfamiliar with the VAD system also necessitated the person repeating their story over again. Support provided by people familiar with the VAD journey was suggested to mitigate this.

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<sup>154</sup> WA VADB 2022-2023 Report, n 13, 57.

<sup>155</sup> For similar observations about the different nature of grief and bereavement with respect to VAD deaths and the difficulties in supporting a loved one through the process (even when supportive of the person's decision), and the need for greater support see, for example, *Conference Report: VAD CON 2023*, n 23, 7; South Australian Voluntary Assisted Dying Board, *Voluntary Assisted Dying in South Australia: Quarterly Report 1 October 2023 to 31 December 2023* (2024) <<https://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/services/primary+and+specialised+services/voluntary+assisted+dying/reporting/voluntary+assisted+dying+reporting>> 3; Go Gentle Australia, "We've Seen Gentle, Beautiful Deaths", n 15; *This is My Stop: Barbara's Story*, n 15; *This is My Stop: Lisa's Story*, n 13.

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*The concern in engaging with different health professionals or different entities is that you have to tell your story over again and you don't know whether you're going to cop a conscientious objector. You don't know if you're going to cop someone that has very goodwill towards you, but has no knowledge of voluntary assisted dying. And so, if someone's grieving that they're like, "Well at least they got to have the death they want". You know the ... at least ... type of sympathy, not empathy people. [Participant 19]*

The absence of dedicated supports has meant other people in the system have taken it upon themselves to provide support.<sup>156</sup> Participants spoke of VAD practitioners, the SWCNS and VAD Coordinators stepping up to provide support given their close connection with the patient. While this level of support was welcomed, and participants praised their efforts, it was noted that such personnel were not necessarily trained, nor had the capacity to offer grief and bereavement support to everyone who needed it.<sup>157</sup> Some participants praised the Queensland approach of a more integrated support service which includes follow-up support in addition to navigation support.<sup>158</sup>

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*I think in Queensland having that alongside ... while they're going through the process of VAD ... to have that support right from the get-go ... I think would be tremendously beneficial. [The SWCNS] check in [and] build beautiful rapports with ... patients and families, but I think [to have that] support alongside them with bereavement counsellors that can really do that work with them [while the SWCNS] are caught up with other work ... I think that would be an amazing thing to have. [Participant 4]*

The emergence of Willow was viewed positively by stakeholders. Willow is a peer support group that offers support through provision of information, private online group meetings for people with lived experience of VAD, and regular in-person catch ups.<sup>159</sup> The SWCNS and some VAD practitioners were referring patients' loved ones to the service as a potential support avenue. However, given the service is unfunded and the network is currently small, it is naturally limited in terms of the level of support it can provide and currently does not extend to providing dedicated grief and bereavement supports.

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156 Sellars et al, n 99, 5.

157 For some reflections on the nature of grief and bereavement support provided by the SWCNS see South Metropolitan Health Service, *This is My Stop: Care Navigator Nikki* (Government of Western Australia) <<https://smhs.health.wa.gov.au/Our-community/Engaging-with-our-community/Navigating-and-understanding-the-voluntary-assisted-dying-experience>> (*This is My Stop: Care Navigator Nikki*).

158 In Queensland, there is a VAD support service known as QVAD-Support. The service is supported by Care Coordinators (similar to WA's SWCNS), who, in addition to fulfilling a care navigation role, provide follow-up care and support. See Queensland Health, *Queensland Voluntary Assisted Dying Support Service (QVAD-Support)* <<https://www.health.qld.gov.au/clinical-practice/guidelines-procedures/voluntary-assisted-dying/support/qvad-support>>.

159 See *Willow – Community and Family Support Through Voluntary Assisted Dying* (Facebook) <[https://www.facebook.com/people/Willow-Community-and-family-support-through-Voluntary-Assisted-Dying/100095063409905/?locale=hi\\_IN](https://www.facebook.com/people/Willow-Community-and-family-support-through-Voluntary-Assisted-Dying/100095063409905/?locale=hi_IN)>.



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*The community support group, Willow, that we've got now ... that's just such a relief now that we can offer that to patients and that they know that's there. We're getting a little bit more specific with what we can offer. Whereas I know when we started it was very general ... Lifeline, Beyond Blue. When I used to give [out those services' details] I didn't really feel that it's a wonderful tool for them. [Participant 4]*

Some participants also shared reflections on the WA VAD memorial service,<sup>160</sup> which was viewed positively amongst participants.

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*I found it was very important for people to hear a story and be able to connect with a story that they weren't alone. And I think the service last year was even bigger than the one before. And there were some beautiful families, and people on the journey, people who'd been through the journey. So, I found that service was invaluable. [Participant 8]*

Participants also spoke of efforts in organisations such as Grief Australia to upskill people to deliver appropriate VAD support.<sup>161</sup> However, participants urged that more work in this area was needed, and some participants also called for greater research in this space.

Some participants suggested that the current need for dedicated supports reflects the fact that VAD is still a relatively new practice. As the system matures and VAD is normalised and integrated more within end-of-life and palliative care, dedicated supports may no longer be necessary.

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*I think it's something that would need to be explored with a view of what [is already available in] the current system and with a view toward building capacity in the system and with due regard to sustainability. You know I think we need to really look at the issue in depth, look at a bit more research and work out a policy solution that's going to be best from a system-wide policy perspective ... The SWCNS is not a grief and bereavement service, however, it does have a role in education and building capacity in the system more generally. The SWCNS has partnered with Grief Australia to build capacity in the grief and bereavement workforce and to create a referral pathway. I think there needs to be more of these kinds of initiatives. From a broader policy perspective, any new grief and bereavement initiative must also not be considered inequitable for other non-VAD patients in terms of the level of service provision such as palliative care patients. Although VAD is new now, eventually it will be normalised. [Participant 17]*

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160 The first VAD Memorial Service was held in September 2022 to mark the first year of VAD. See WA VAD Board, *Quality Practice Series #3* (Western Australian Government: Department of Health, December 2022) <<https://www.health.wa.gov.au/~media/Corp/Documents/Health-for/Voluntary-assisted-dying/Quality-Practice-Series-3-Dec-2022.pdf>> 1.

161 For example, Grief Australia has held webinars and workshops about the VAD grief experience and possible interventions. See Grief Australia, *The Grief of Families and Friends After a Voluntary Assisted Death* <[https://www.grief.org.au/ga/Content/Information-Sheets/Grief\\_of\\_Families\\_and\\_Friends\\_After\\_a\\_Voluntary\\_Assisted\\_Death.aspx](https://www.grief.org.au/ga/Content/Information-Sheets/Grief_of_Families_and_Friends_After_a_Voluntary_Assisted_Death.aspx)>.

### *Issues identified*

Appropriate grief and bereavement support is needed for people whose loved ones have gone through the VAD process. While grief and bereavement are an expected and natural part of death, the specific nature of VAD (and the fact it is a new end-of-life choice) means people may need dedicated support that is sensitive to the VAD context.

### *Recommended responses*

In Recommendation 21 (below), the authors specifically address this issue in the context of the wider VAD workforce, namely that statewide services should be resourced to provide grief and bereavement support to family and carers. However, the authors recognise that people will seek this support from a range of settings, including from general grief and bereavement support services. The DoH, in conjunction with the SWCNS (given its experience), may wish to consider whether it can provide resources and/or advice about VAD to these other services so that their support can be sensitive to the context of VAD (e.g. understanding how issues such as anticipatory grief can arise with VAD deaths).

## **Recommendation 18**

**Review existing grief and bereavement supports currently available to assess suitability and availability to support individuals affected by a VAD death.**

### **4.6 Contact person**

Under the WA VAD Act, a patient must appoint a contact person.<sup>162</sup> The contact person can be any person aged over 18.<sup>163</sup> The Board is required to provide information to the contact person that explains their obligations.<sup>164</sup> Other than providing that information, there is limited engagement by the VAD system with the contact person either to check in or to provide an opportunity for the contact person to clarify any points of concern. Formal follow up is only likely to occur if the contact person is at risk of breaching their obligations to dispose of the substance.<sup>165</sup>

### *Participants' submissions and evidence*

Participants expressed concern about the nature of the contact person role and the burden placed on them.<sup>166</sup> Participants noted that the role was often misunderstood, and that some people did not necessarily appreciate the level of responsibility and the nature of obligations associated with that role. Participants advised that the SWPS commonly tried to do some education with the contact person about their role, but this was not part of the formal VAD process. The limited follow-up with the contact person (outside the contact by the VAD Board Secretariat in relation to the return of the VAD substance, if needed) was also criticised. Participants suggested that outside the informal support from the SWPS, current processes meant that the contact person was largely unsupported, despite the significance of their role. This was perceived to be particularly problematic if the contact person was the patient's loved one.

<sup>162</sup> *Voluntary Assisted Dying Act 2019* (WA) s 65.

<sup>163</sup> *Voluntary Assisted Dying Act 2019* (WA) s 65(2).

<sup>164</sup> *Voluntary Assisted Dying Act 2019* (WA) s 149.

<sup>165</sup> For examples of the contact person's obligations see *Voluntary Assisted Dying Act 2019* (WA) ss 67, 105.

<sup>166</sup> The confronting and challenging nature of the contact person role has previously been identified. See *Quality Practice Series #5*, n 113, 3; *Victorian VADRB Report June 2019-December 2019*, n 99, 8.

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*I think the contact person role is really, really challenging. I don't think there is enough recognition about the load that that puts on the person who is doing the contact person role. There's no formal requirement for follow up in any way, shape or form, with that person outside of the legal responsibilities ... I think we leave them out to dry and we don't often make space for them to have their own conversation, about what that means for them before they accept the role and in the time afterwards ... So, they don't often have access to the kind of support that they often need when they're providing that kind of care and support for the person. [Participant 3]*

*There's nothing in the VAD Act discussing the need to do education for the contact person. Again, pharmacy have taken that role on but whether or not that's something that should be formalised. [Participant 11]*

*In WA we don't follow up with the contact person unless they are at risk of breaching their obligations under the Act, in that we are aware that their substance has not been consumed .... And the mitigation is that the volume of substance is considered to be low enough that the person is consuming it all in one shot, and so there would not be leftovers ... I know then that in other jurisdictions they ring every contact person after a death. And that has been a source of useful information and potential risk mitigation. But it's also been something that is traumatic often for [the] contact person and [the] Secretariat ... calling someone so soon after the death of a loved one too. [Participant 19]*

### *Issues identified*

The contact person plays an important role in the WA VAD system. Participants raised several issues regarding the burdens placed on them, and whether they are adequately supported in their role.

### *Recommended responses*

The authors endorse calls for education of persons fulfilling the contact person role to ensure they are aware of their legal obligations, as well as the need for them to be supported. The authors acknowledge the efforts by the SWPS to educate the contact person, but note this is not the core business of the SWPS. The DoH may wish to consider whether current practices should be more formalised, including whether (and when) contact persons should be contacted after a VAD death. Some of the issues raised by participants relate to wider support needs for contact persons which are also addressed by observations and recommendations above in relation to grief and bereavement (see Recommendation 18).

## 4.7 Death certification<sup>167</sup>

Section 44 of the *Births, Deaths and Marriages Registration Act 1998* (WA) requires a Medical Certificate of Cause of Death (MCCD) to be completed by a medical practitioner who is responsible for the person's care immediately before death or has examined the deceased body.<sup>168</sup> In cases where a nurse practitioner or registered nurse are present for the patient's death, they can certify life extinct, but a medical practitioner must complete the MCCD.<sup>169</sup> The MCCD must not include any reference to VAD, even if the death resulted from the VAD substance.<sup>170</sup> The policy intention behind this restriction is to protect the person's privacy and reflect that the person died from their underlying illness.

### *Participants' submissions and evidence*

Some participants advised that there had been barriers to getting the MCCD completed following a VAD death.<sup>171</sup> This typically occurred in cases where a nurse practitioner was taking on the role of the administering practitioner, and the coordinating or consulting practitioners were not available to certify the death. While in such cases, contacting the patient's GP was an option, if the GP had a conscientious objection to VAD or were not confident about the cause of the patient's death, they may be reluctant to complete the certificate.<sup>172</sup> One solution offered by participants was to permit nurse practitioners to complete the death certificate, particularly if they were the administering practitioner.

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*There are issues for nurse practitioners in organising a death certificate for the patient ... A nurse practitioner ... can't complete a death certificate ... [they can] complete a Life Extinct form which goes with the patient to the funeral home. But if ... your coordinating practitioner is not in the country, so is not able to do the death certificate for you, and then your only other person is the GP who is a conscientious objector, or refuses to do the death certificate, you're stuck because you then don't have a death certificate for the patient. And so, the funeral home then, in a couple of cases, have put pressure on the family going, "Well we can't organise this person's funeral until we've got this death certificate". And it's just unnecessarily holding up the process.*  
[Participant 29]

Moreover, participants reported that mixed views have been expressed about whether reference to VAD on the patient's death certification documentation should be permitted.<sup>173</sup>

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*Death certificates hurt us as well ... we are hearing from patients repeatedly that they want voluntary assisted dying on their death certificate, they feel very strongly about it that they don't want the disease to be listed as the thing that kills them. But then correspondingly we have patients who are so relieved to know that it's not on their death certificate. And practitioners that fall on both side of the fence ... I think that is really challenging and it needs a lot more care and consideration. It's given a lot of debate in Parliament, but I think our understanding of the impact of that has changed significantly.* [Participant 3]

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167 The authors note the difference between a Medical Certificate of Cause of Death which is completed by a medical practitioner and the death certificate which is issued by the Registry or the Courthouse. However, participants used the term death certificate as an umbrella term to refer to both documents.

168 Unless the death is reportable to the coroner. See section 44(5) of *Births, Deaths and Marriages Registration Act 1998* (WA).

169 *Quality Practice Series #5*, n 113, 3; *WA VAD Guidelines*, n 49, 65.

170 *Voluntary Assisted Dying Act 2019* (WA) s 82(6).

171 *Quality Practice Series #5*, n 113, 3.

172 Refusal to complete death certification in cases of VAD deaths have been previously reported see White et al, n 76.

173 Go Gentle Australia, 'It's a New System and There Are Still Some Challenges', n 144; *Victorian VADRB Report July 2022- June 2023*, n 26, 29.

### *Issues identified*

Participants identified that logistical challenges sometimes arose in finding a medical practitioner to certify a VAD patient's death, particularly in cases where the administration was performed by a nurse practitioner. There was also ambivalence about whether death certification documentation should include mention of VAD.

### *Recommended responses*

The DoH should consider addressing some of the logistical issues raised in relation to delays associated with certification of death, due to the inability (or unwillingness) of some medical practitioners to certify patients' deaths in cases where they accessed VAD.

Whether VAD should be recorded on death certification documentation was extensively considered when the law was designed and debated. In the absence of a clear consensus on the best approach, the authors are not making a recommendation on this issue. However, it may be an issue for future consideration should a settled preference within the WA community emerge. If ambivalence about this issue continues, consideration could be given to providing people with the option, depending on personal preference, for death certification to include a reference to VAD.

# Chapter 5: VAD workforce

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Safe and effective delivery of VAD is reliant on a VAD workforce comprising VAD practitioners, the SWCNS, the SWPS, VAD Board and Secretariat and institutional VAD supports (e.g. VAD Coordinators). The current WA VAD workforce has consistently been commended for their commitment to VAD and person-centred care, as well as their compassion.<sup>174</sup> The demand for VAD in WA has been higher than anticipated and is likely to increase over time as awareness of VAD grows in the community.<sup>175</sup> There is also a higher-than-expected number of practitioner-administered deaths which places greater demand on the workforce.<sup>176</sup> For patients to continue to have this end-of-life option available to them, it is important that there is a sufficient workforce to meet community demand, and that the workforce is appropriately supported to carry out this work. This chapter explores both of these issues.

## 5.1 Expand the VAD workforce, including in regional areas

According to the most recent VAD Board Report, 68 medical practitioners and 1 nurse practitioner have participated in the VAD process as either a coordinating, consulting or administering practitioner. Most practitioners are likely to have acted as a coordinating, consulting or administering practitioner for between 2-10 patients.<sup>177</sup> This distribution of provision places a high burden on a small number of practitioners, and efforts are needed to increase the VAD workforce including in regional areas. The need to expand the workforce has previously been identified by the WA VAD Board.<sup>178</sup>

### *Participants' submissions and evidence*

An important barrier to the involvement of medical practitioners in the VAD workforce is the lack of remuneration. Currently, there is little financial incentive for practitioners to undertake the mandatory training and to act as VAD practitioners.<sup>179</sup> Although not in effect at the time of data collection, participants noted the DoH's plan to establish remuneration packages for VAD practitioners, scheduled to take effect in July 2024.<sup>180</sup> This was viewed positively by participants, although many suggested that this would only offer a short-term solution, and changes at the federal level were necessary. Significantly, participants suggested that until there was financial incentive to do this work, there was unlikely to be a further increase in number of VAD practitioners.

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*[GPs] can't spend 12 hours per patient for two hours remuneration ... we're not going to get new providers in until that's addressed. [Participant 30]*

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174 See, for example, Blackwell, n 15; WA VADB 2021-2022 Report, n 13; WA VADB 2022-2023 Report, n 13; Bourke, n 15; Colgan, n 15; Go Gentle Australia, "Eternally Thankful", n 15; Go Gentle Australia, "Stephen had a Peaceful Death", n 13; Lundie, n 15; *This is My Stop: Barbara's Story*, n 15; *This is My Stop: Dan's Story*, n 15; *This is My Stop: Gina's Story*, n 15; *This is My Stop: Lisa's Story*, n 13; *This is My Stop: Sam's Story*, n 15.

175 Blackwell, n 15; Haining, Willmott and White, n 4, 732-733; Hunt, n 33, 209; WA VADB 2021-2022 Report, n 13; Bourke, n 15; Elton, n 15; Lundie, n 15.

176 CM Haining et al, "Access to Voluntary Assisted Dying Requires Fair Remuneration for Medical Practitioners" (2023) 218(1) *Medical Journal of Australia* 8; Towler, n 15.

177 WA VADB 2022-2023 Report, n 13, 14.

178 WA VADB 2021-2022 Report, n 13, 37.

179 McLaren and Mewett, n 30, 115-116; Rutherford, Willmott and White, n 26, 1070; Sellars et al, n 99, 6.

180 *Quality Practice Series* #8, n 3.

The dearth of VAD practitioners in WA creates challenges for the timely delivery of VAD particularly in regional areas.<sup>181</sup> Regional access to VAD has been facilitated, to some extent, through the regional access support scheme (RASS).<sup>182</sup> However, it is not always feasible for metropolitan practitioners to travel regionally, and hence increasing local providers is considered preferable for sustainability.<sup>183</sup> Participants also noted that there are some limitations of the scheme. For example, it would not fund the travel of a specialist who may be needed to help inform a prognosis but was not conducting their own eligibility assessment, nor would it fund practitioner travel if videoconferencing could be used (despite practitioner preference to see patients face to face for aspects of the process).

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*[Regional Town X] got a bit short of practitioners, or the Navigators don't know all the practitioners in [Regional Town X]. So, I've been getting asked to go there, which is 78 Ks [kilometres] for me ... I get paid for my mileage and I've been paid reasonably promptly. So that's been very good, but I've been told, "If you could do it by video conference, you should be doing it by video conference and they shouldn't allow you to claim the RASS" ... I prefer to see them by person, I'd rather not get paid that way ... I prefer that I just see my local community. I just occasionally help out if I've got capacity. [Participant 32]*

Participants also showed support for expanding the roles of other health practitioners in the VAD process.<sup>184</sup> Firstly, participants were of the view that authorised nurse practitioners were more likely to be involved as administering practitioners if they were involved in more of the VAD process. Participants suggested that expecting a nurse practitioner to step in at the 'pointy end' of the process was unreasonable, unethical and emotionally challenging. Participants noted that in some cases efforts were made to involve the nurse practitioner earlier in the process (e.g. sitting in on consults) to provide them an opportunity to form a relationship with the patient and the family.

Participants also expressed support for nurse practitioners to have a greater role in the process (namely assessing eligibility), given their level of expertise and experience.

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*I think nurse practitioners probably ... wanted more of a role within VAD, which hasn't happened ... but, I think, yes, a lot of the nurse practitioners aren't involved because, yes, they don't want to be there right at the end where they haven't had contact with the patient before. [Participant 29]*

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181 The dearth of the VAD workforce in WA has previously been identified see Haining, Willmott and White, n 10; *WA VADB 2021-2023 Report*, n 13, 37; Towler, n 15; *WA VADB 2022-2023 Report*, n 13, 4; Cox, n 22; P Law, "Voluntary Euthanasia: Alarming Number of VAD-Trained Doctors In WA Revealed", *The West Australian*, 1 July 2021 <<https://thewest.com.au/news/health/voluntary-euthanasia-alarming-number-of-vad-trained-doctors-in-wa-revealed-ng-b881917671z>>; Lundie, n 15; T Robinson, "Goldfields GPs Yet to Get on Board with Voluntary Assisted Dying Program", *Kalgoorlie Miner*, 3 July 2021 <<https://www.kalminer.com.au/news/kalgoorlie-miner/goldfields-gps-yet-to-get-on-board-with-voluntary-assisted-dying-program-ng-b881918247z>>.

182 Haining, Willmott and White, n 10.

183 Haining, Willmott and White, n 10; Lundie, n 15.

184 Previous research amongst WA stakeholders demonstrated support for expanding the role of health practitioners see Haining, Willmott and White, n 4, 734-735. For further commentary on expanding the role of health practitioners in the VAD process see J Hewitt, L Grealish and A Bonner, "Voluntary Assisted Dying in Australia and New Zealand: Exploring the Potential for Nurse Practitioners to Assess Eligibility" (2023) 30(1) *Collegian* 198; R Jeanneret and S Prince, "Nurses and Voluntary Assisted Dying: How the Australian Capital Territory's Law Could Change the Australian Regulatory Landscape" [2024] *Journal of Bioethical Inquiry* (online first).



Furthermore, some participants suggested that senior registered nurses should be able to act as administering practitioners, as occurs elsewhere in Australia.<sup>185</sup>

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*I know that in other states it's possible for other senior nursing staff to fill administering roles particularly which I think is worth a conversation for us. [Participant 3]*

A final issue about expanding the VAD workforce raised by participants related to the current CEO practitioner requirements. The CEO requirements<sup>186</sup> for participating practitioners include the minimal number of clinical hours per registration period, the need for two professional referees to ascertain suitability, and the requirement not to have notifications, conditions, undertakings or reprimands on one's registration record. Additional requirements apply for overseas-practitioners. The authors note this issue falls outside the scope of the Panel's Review, but report on participants' views for completeness.

Participants had mixed views about these requirements.<sup>187</sup> Some participants suggested that the CEO requirements had a deterrent effect on practitioners being involved. There was also a degree of frustration surrounding the way the CEO requirements were conceived, including the view that the Director General had an unfettered discretion to assess suitability of practitioners to participate in VAD. Conversely, other participants endorsed the CEO requirements because they introduced a level of safety within the system. In particular, participants noted that the WA Government does not control access to VAD through a state-issued permit like some other Australian states and considered that these CEO requirements served as a safeguard about who was providing VAD in lieu of that.

### *Issues identified*

The demand for VAD in WA has been higher than expected. This has had a significant impact on the workloads of VAD practitioners, especially participating practitioners who are often completing this work alongside other clinical commitments. The VAD workforce needs to be expanded including in regional areas to meet current and future patient demand for VAD.

### *Recommended responses*

The authors acknowledge the actions to date by the DoH to encourage and incentivise the provision of VAD, for example, through roadshows and community forums to raise awareness and through establishing new remuneration packages as well as remunerating practitioners via the RASS.<sup>188</sup> The authors support such ongoing efforts, but also recommend DoH develop additional strategies to increase the number of VAD practitioners.

The authors acknowledge potential limits on the scope of the Panel's Review, but recommend future reviews consider extending the roles for both nurse practitioners and nurses. Models adopted in other states such as permitting senior nurses to act as an administering practitioners and, most recently, permitting nurse practitioners to assess for eligibility in the Australian Capital Territory would be worthy of consideration.<sup>189</sup>

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185 Under Queensland's and Tasmania's legislation registered nurses can act in administering practitioners if they have completed the mandatory training and have at least 5 years' experience. See *Voluntary Assisted Dying Act 2021* (Qld) s 83 and *End-of-Life Choices (Voluntary Assisted Dying) Act 2021* (Tas) ss 62-63.

186 Department of Health, *Voluntary Assisted Dying Act 2019 (WA): CEO Practitioner Eligibility Requirements* (Western Australian Government, 2024) <<https://ww2.health.wa.gov.au/-/media/Corp/Documents/Health-for/Voluntary-assisted-dying/CEO-Practitioner-Eligibility-Requirements.pdf>>.

187 Mixed views around current accreditation requirements have been reported elsewhere see A Miller, "Support the Community and your Colleagues" (2022) 62(1) *Medicus* 32-33; Haining, Willmott and White, n 4, 735-736; Lundie, n 15.

188 Haining, Willmott and White, n 10; *Quality Practice Series* #8, n 3. The range of initiatives to incentivise provision were also canvassed in the Government's Response to recommendations from the WA VAD's Board's 2021-2022 Annual Report see A-J Sanderson, *Government Response to the Recommendations of the Voluntary Assisted Dying Board Annual Report 2021-2022*. <[https://www.parliament.wa.gov.au/publications/taledpapers.nsf/displaypaper/4111939aaecbf9255f8ca898482589aa002918d8/\\$file/tp+1939+\(2023\)+sanderson+-+bms+-+tabled+paper+-+government+response+to+the+voluntary+assisted+dying+board%E2%80%99s+annual+report+-+final.pdf](https://www.parliament.wa.gov.au/publications/taledpapers.nsf/displaypaper/4111939aaecbf9255f8ca898482589aa002918d8/$file/tp+1939+(2023)+sanderson+-+bms+-+tabled+paper+-+government+response+to+the+voluntary+assisted+dying+board%E2%80%99s+annual+report+-+final.pdf)>.

189 As noted above, under Queensland's and Tasmania's legislation registered nurses can act in administering practitioners if they have completed the mandatory training and have at least 5 years' experience. See *Voluntary Assisted Dying Act 2021* (Qld) s 83 and *End-of-Life Choices (Voluntary Assisted Dying) Act 2021* (Tas) ss 62-63. In the ACT, one of the practitioners who assess eligibility can be a nurse practitioner see *Voluntary Assisted Dying Act 2024* (ACT) s 89.

## Recommendation 19

Develop strategies and explore opportunities to increase the VAD workforce including:

- adequate workload recognition or remuneration for medical practitioners providing VAD; and
- payment to complete the mandatory VAD training.

## Recommendation 20

Future reviews of the WA VAD Act should explore the feasibility of expanding the roles of other health practitioners in relation to VAD such as:

- nurse practitioners to assess eligibility; and
- senior nurses to act as administering practitioners.

### 5.2 Supporting and sustaining the VAD workforce

As well as expanding the VAD workforce, it is critical to ensure that the existing VAD workforce is supported to continue its VAD work. The workforce here refers to all health practitioners working to deliver VAD as an end-of-life option to individuals who choose it. Failure to appropriately support the existing workforce may lead to attrition and result in an unsustainable VAD service. While many practitioners observe that the nature of the work is rewarding, it is also recognised that the provision of VAD is resource intensive and can take an emotional toll.<sup>190</sup> A failure to adequately support practitioners and service delivery can also put sustainability of the VAD system at risk. Two important issues were raised by participants relevant to the sustainability of the VAD workforce: the need to provide the VAD workforce with emotional and practical supports; and the need for VAD practitioners to be adequately remunerated and their work valued.

#### *Participants' submissions and evidence*

- Need for emotional and practical supports

Many participants identified that the level of support currently offered was inadequate. Participants observed that people in the VAD system were commonly going above and beyond to support a patient's VAD journey (including being present during administration, visiting patients and their loved ones on multiple occasions and providing grief and bereavement support). Although the efforts of individuals involved in the delivery of VAD were pivotal in supporting a patient and family to navigate the VAD process, these efforts took an emotional toll on those individuals. This is exacerbated by the long hours, many of which are not remunerated, that are worked by many, and the absence of adequate supports.

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*I don't think we do grief and support counselling very well for anybody in the system.*

[Participant 25]

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<sup>190</sup> Such sentiments are consistent with what has been expressed elsewhere see, for example, Rutherford, Willmott and White, n 26, 1070; Sellars et al, n 99, 6-7; Bourke, n 15; Go Gentle Australia, "It's a New System and There Are Still Some Challenges", n 144; Lundie, n 15; John, n 131.

The need to support VAD practitioners, in particular, was widely observed by participants. It was acknowledged that medical practitioners invest heavily in the process and, given the dearth of providers, some practitioners were taking on high patient loads to ensure demand was being met. Participants noted that high workloads posed a risk of burnout and attrition. This will also affect the ability to meet patient demand.

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*We know that some of the participating practitioners do take time out. They tell the Statewide Care Navigator Service, "I need a break". And the Care Navigator Service are also very aware of the individual practitioners, and they can see where burnout [is] beginning to appear in some of them. It's a great worry for us because we've had a smaller cohort of very active practitioners. And then a larger cohort where people have participated with one, two or three cases or so. And when we lose one or two of the very active practitioners who've done 10, 20, 30 cases that's a worry because they're [our] most experienced practitioners. [Participant 26]*

*We've really almost left it to [doctors to] sort of provide their own self-support arrangements really. And I think we're very fortunate that we have good quality people in the Care Navigator Service and in the leadership of the Community of Practice that sort of do enable that to a reasonable degree. But we don't really have a measure of how well our doctors are supported in this sense ... to my mind there isn't enough coordinated support. [Participant 23]*

It was noted by some participants that the statewide services and institutional VAD staff offer support to practitioners where possible.<sup>191</sup> For instance, it was noted that staff from the SWCNS would often attend practitioner administration to help support the practitioner by managing the patient's family. This provided the space for the practitioner to focus on the patient and the administration process. Similarly, the SWPS were seen as a form of peer support. They would discuss with the practitioner potential strategies and avenues for support and self-care, and commonly make follow-up calls after administration with the aim to ascertain feedback about the SWPS service, which also provided medical practitioners with an opportunity to debrief.

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*Because [WA] have such a high proportion of practitioner administration [the Pharmacy] definitely see that as a big role from [their] perspective, because [they are] often the ones who saw [the practitioner] immediately before they left. [The Pharmacy] offer feedback forms and offer phone calls afterwards. [The Pharmacy] ... will [ask] practitioners ... what are you going to do after the admin to look after yourself? [The Pharmacy provide] some suggestions about what other practitioners do [and] about maybe putting some time aside ... when a practitioner calls about their next patient. [The Pharmacy] often ask about how things went with the last patient. [The Pharmacy] have practitioners dropping in most days and so [they] really do see [themselves] as a good resource for that, whether or not [they are] well equipped and well trained to do that. [Participant 11]*

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<sup>191</sup> For discussion of supports available to VAD practitioners, in addition to generic supports available see Hon Sue Ellery Parliamentary Debates, 14 February 2023, Legislative Council <[https://www.parliament.wa.gov.au/Hansard/hansard.nsf/0/9E9E729F5742B8FE48258975001F9B38/\\$file/C41%20S1%2020230214%20All.pdf](https://www.parliament.wa.gov.au/Hansard/hansard.nsf/0/9E9E729F5742B8FE48258975001F9B38/$file/C41%20S1%2020230214%20All.pdf)> 88.

The Community of Practice was also identified as a critical form of support for VAD practitioners. Participants spoke favourably of the Community of Practice and how it has evolved over time to be inclusive of those within the VAD system (e.g. SWCNS and SWPS), rather than limiting its membership to medical practitioners.<sup>192</sup>

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*[The Community of Practice meetings] we have every month ... They're getting bigger and bigger because more people just love coming, it's great networking for us all ... I think it's really supportive and we can always ... we've got a little sub-group off that which we sort of meet every couple of months at one of the doctors' houses ... I think it's a fantastic group. We all get on really well and would not have the hesitancy in flinging a message or whatever if you're wanting support or help from one your other colleagues. [Participant 29]*

While these forms of support were highly regarded by practitioners, participants identified that there is disparate resourcing of support networks for the workforce.<sup>193</sup> Indeed, participants acknowledged that not all practitioners were necessarily linked into such supports. Participation in the Community of Practice is not mandatory, nor is connection with the SWCNS. Hence, practitioners who were not accessing these forms of support could feel isolated. Similarly, it was noted that while some practitioners who are associated with health service providers may have access to generic forms of employee assistance program supports, not all practitioners, including those working in general practice, will have access to them. There was also suggestion that regional practitioners could feel isolated due to their lack of connection.

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*I mean I feel this is a calling. And I feel very connected to the other people. But I am very lonely down here [in Regional Town X]. [Participant 32]*

- Need for practitioners to be adequately remunerated and their work valued

The lack of appropriate remuneration for the VAD workforce has been repeatedly criticised.<sup>194</sup> Participants reinforced frustrations about the lack of formal recognition for VAD practitioners' efforts, both in terms of the value of their work and in the form of remuneration. The workforce devotes a significant amount of time carrying out VAD-related work. The most recent WA VAD Board Report estimated that VAD practitioners were committing a minimum of 8.5 hours per patient (including contact and non-contact activities) when completing the request, assessment and administration process.<sup>195</sup> Failure to properly pay VAD practitioners for their work has meant that many carry out this service altruistically. Many VAD practitioners also carry out their VAD work over and above their usual work allocation. For regional patients for whom a local provider is not available, the time commitment to travel to these patients (in cases where videoconferencing is not appropriate) is significant and not always feasible.<sup>196</sup>

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192 In this regard, participants' observations were consistent with research reported elsewhere see Haining, Willmott and White, n 4, 740.

193 Such sentiments have been reflected in empirical research coming out of Victoria see, for example, Rutherford, Willmott and White, n 26, 1070; Sellars et al, n 99, 6-7.

194 The lack of appropriate remuneration for the VAD workforce has been identified and repeatedly criticised. See, for example, Haining et al, n 176; *Conference Report: VAD CON 2023*, n 23, 9; *National VAD Survey*, n 23; *Queensland VADRB Annual Report 2022-2023*, n 23, 29; *Tasmanian VAD Commission Six Month Report 2022-2023*, n 99, 20-29; *Victorian VADRB Report July 2022- June 2023*, n 26, 31; *WA VADB 2021-2022 Report*, n 13, 37; *WA VADB 2022-2023 Report*, n 13, 56; Bourke, n 15; Brennan, n 75; John, n 131.

195 *WA VADB 2022-2023 Report*, n 13, 56.

196 Haining, Willmott and White, n 10.

These practices have led practitioners to question whether their VAD work is sufficiently valued. Participants suggested this toll over time has led some practitioners to cut back their participation in VAD, leading to significant attrition amongst an already small pool of trained doctors. The lack of remuneration has also led to a two-tiered system for patients: greater access for those who can afford a fee-paying doctor; and less access for those who cannot.<sup>197</sup>

Participants acknowledged that the WA Government has attempted to address this problem by establishing remuneration packages (to take effect from July 2024),<sup>198</sup> but expressed concern that this would likely only be a temporary or partial solution. Indeed, multiple participants highlighted that ultimately federal recognition through the inclusion of a dedicated Medicare Benefits Schedule item number was needed.

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*Practitioners' sustainability tension is to be our primary point of concern. I know that our Department is working on remuneration packages for practitioners that we hope to see available shortly. But the complete absence of recognition of the worth of the work that they do has been incredibly challenging and has definitely seen some significant attrition of these amazing doctors who do this work. And the capacity to continue to provide this care without anyone saying, "Yes, your time is worthwhile, and you are required to have specialist skills and experience to do this work and you do it well", is really difficult. That has led to a bit of a two-tiered access system now that we're continuing to see emerge where various people who can afford to pay a fee [for a VAD] doctor ... because doctors need to charge fees to be able to pay their mortgage, and patients who can't afford a fee-paying doctor, so then wait longer for access, can't get access. [Participant 3]*

It was also identified that while the VAD system appears to be operating smoothly now, this was the product of the exceptional quality of the personnel currently within the VAD system and their current willingness to undertake this volume of work. These individuals included health practitioners, statewide staff, VAD Coordinators within institutions, VAD Board Secretariat and VAD Board Staff. However, participants identified that there is a risk when the system's sustainability is dependent on individuals going above and beyond in performing their roles.

### *Issues identified*

The deep commitment of the VAD workforce to support VAD in WA and carry out VAD work is striking. However, more is needed to support these individuals. This is not only to ensure their wellbeing but also to ensure system sustainability as, without them, the VAD system cannot operate.

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197 WA VADB 2022-2023 Report, n 13, 56.

198 Quality Practice Series #8, n 3.

### *Recommended responses*

A system review is needed to address the two issues identified above: emotional and practical supports to address VAD workforce wellbeing; and adequate remuneration and recognition of the VAD work undertaken. Some of this work has begun with the new DoH remuneration scheme for VAD practitioners. Part of this recommendation also relates to the resourcing of statewide services to provide the grief and bereavement support discussed earlier in the Report.

## **Recommendation 21**

**Review current VAD practices and workload of existing VAD workforce (including VAD providers and those who have a role in VAD such as statewide services and VAD Coordinators) to ensure:**

- participating practitioners are provided with adequate workload recognition or remuneration for providing VAD;
- statewide services are resourced sufficiently to provide required services including statewide travel and grief and bereavement support to family and carers; and
- access of the VAD workforce to services to support their self-care and wellbeing.

# Chapter 6: VAD system design

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This chapter considers the VAD system as a whole and reflects on some of the structures in place that make VAD possible both within the community or within an institutional setting. The chapter considers the structure and location of statewide services, management of VAD within a health setting, information-sharing and privacy constraints, integrating VAD within health care and palliative care and the relationships and interaction between the VAD Board, its Secretariat and the DoH.

## 6.1 Structure and location of statewide services

In WA, the VAD system is supported by two statewide services, the SWCNS and the SWPS. The statewide services are managed by two metropolitan health service providers, the South Metropolitan Health Service and the North Metropolitan Health Service respectively. These services are designed to operate only during business hours,<sup>199</sup> and they service the entire state. There are Regional VAD leads in each of the regions, but there are no designated regional Statewide Care Navigators, nor regional Statewide Pharmacy hubs.<sup>200</sup>

### *Participants' submissions and evidence*

As noted above, there was universal high praise from participants for the statewide services, and the professionalism and compassion of staff within those services.<sup>201</sup> However, several suggestions were made for how the services might be improved.

- Merging the statewide services

Participants had mixed views on structural arrangement of the statewide services. Some participants suggested that the co-location and merging of the statewide services would help streamline operations. Some participants referred to the Queensland model as worth considering.<sup>202</sup> But other participants were of the view that now that the structures supporting VAD in WA had already been established, it would be impractical to merge the services.

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199 Although, it is noted that sometimes regional travel and flight availability has necessitated that these services operate outside of hours at times.

200 Haining, Willmott and White, n 10.

201 The pivotal role of the statewide services in the functioning of the VAD system and, in particular, supporting its accessibility for patients, is also acknowledged in the literature see Sellars et al, n 99, 7; White et al, n 26, 214-215; Willmott et al, "Participating Doctors' Perspectives on the Regulation of Voluntary Assisted Dying in Victoria: A Qualitative Study", n 26, 127.

202 In Queensland, QVAD-Support (service that provides advice and support to people wanting to access VAD in Queensland and is staffed by care coordinators) and QVAD-Pharmacy service are both operated out of the same health service provider, Metro South Health. See Queensland Health, n 158; Queensland Health, *Queensland Voluntary Assisted Dying Pharmacy Service (QVAD-Pharmacy)* <<https://www.health.qld.gov.au/clinical-practice/guidelines-procedures/voluntary-assisted-dying/voluntary-assisted-dying-substances>>.



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*I think definitely the Queensland model is much more advanced in that way than ours ... there's so much duality between [the SWCNS and SWPS] roles that it would allow for a little bit more scope when one team is busy or the other team is busy. [The SWPS] do sometimes still do joint visits with the [SWCNS] and work in collaboration. [The services] have weekly meetings. [There have been attempts to try] to set up the patient information system to speak between [the two services] so there's a little bit more collaboration. [Participant 11]*

*If we were going to do it again, I'd say combine it generally. But ... it's very, very hard to do changes like this once they're in. Because you've got infrastructure problems; you've got budget problems; you've got personality elements around it. This will not get changed unless it's significantly broken ... I do think that there's advantages to a point with our model relative to others. With our model you'll get hyperfocus from a Chief Pharmacist who's very aware of navigating complex medicines problems because they come under that portfolio. But you would never want a Chief Pharmacist managing a Care Navigator Service because that's well outside their scope ... I think if you've got that sequestered under a Care Nav role, there might not be the organisational knowledge or the ability to do a lot of complex change management as it relates to VAD medicines. [Participant 10]*

- Centralised or decentralised statewide services

Participants also offered reflections on the centralised nature of the statewide services. They did not consider the centralisation of the SWPS was necessarily acting as a barrier to timely access to VAD substances. However, some conceded that there were some logistical barriers because of travel constraints of individual practitioners and flight availability. One participant suggested that utilising private providers for flights may help to address some of these issues.

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*Where we come into trouble ... is when Qantas is striking and there's no other option ... whether or not there are some other airlines that [could be considered] that are being used currently in a private capacity. [Participant 11]*

The possibility of alternative models, such as the hub-and-spoke model, were raised by participants, but there was not universal support for change.<sup>203</sup> For those supporting no change to the current structure, some pointed to perceived feasibility issues and resourcing constraints, as well as the absence of steady demand in particular regions. However, other participants could see the benefit of permitting storage of prepared kits in regions with higher demands (e.g. Great Southern region). This approach would have the added advantage of limiting the need to store the substance in a practitioner's home (and mitigate some of the concerns with respect to storage practices discussed in 4.4), in cases where the substance was dispensed early to facilitate access to the substance if the patient deteriorated quickly.

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203 Such reflections are consistent with other literature see Haining, Willmott and White, n 10.

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*I think one of the things at the moment is for a start we don't have enough regular supplies to any one region. We'll have a peak in one area and then we don't have any supplies there for two months. So, supporting someone to work in that region, having medication supplied in that region and managing the expiries, supporting that person from a debrief and a grief and bereavement from a staff member point of view I think would be really difficult ... Whether or not there's some other options for supporting storage of a kit that [has] already supplied somewhere external to the practitioner's home. For instance, we have some lockers like the Australia Post lockers that we currently use for practitioners to drop off prescriptions. [Participant 11]*

One participant suggested that the medications used for VAD, especially those used in the practitioner IV protocol, were not unusual and could appropriately be dispensed by a local pharmacy in regional areas.

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*I mean it's certainly not efficient to me, that two human beings spend six hours in a car to come to me when the IV drugs are next door in my theatre, or they're in my [Emergency Department]. So, for the IVs, delivering to me, who's done lots now ... it seems ridiculous to me that they have to come and give me the drugs when I could get them from next door. [Participant 32]*

Some expressed a desire for VAD Care Navigators to be located in some of the regions. In one of the regions there were a growing number of VAD practitioners who were not known to the SWCNS (because they did not provide consent for their details to be released to the SWCNS). Hence, when VAD enquiries were coming through the SWCNS, the RASS was being used to service this region instead of these local practitioners. This was regarded as a waste of time and resources. In other cases, where VAD requests were coming from the community in a particular regional area, there was a reliance on particular VAD practitioners to coordinate appointments and link patients up with other practitioners, which meant they were unofficially fulfilling a Navigator type role unfunded.

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*I get quite a few where no Navigators are involved, then I end up doing the Navigator role, I guess down here ... Because sometimes involving the Navs just is an added layer of complexity to me. So then I'm organising the day – I'm having to negotiate with both the patient and the Navigator and it makes my job harder, not easier. If there was a local Navigator, they would be doing that job. [Participant 32]*

- Resourcing levels

There was an overwhelming call for greater resourcing of the statewide services (also noted earlier in recommendations to provide supports for the wider VAD workforce).<sup>204</sup> While both services were currently able to meet demand, there was little, if any, time to devote to quality improvement initiatives, training and upskilling. Some participants observed that they needed to deprioritise some activities (such as follow-up checks and grief and bereavement support) because of a lack of time.

Some suggested initiatives to support statewide service staffing during periods of high-demand or when staffing levels were down. One solution posed by a participant was to employ health service VAD Coordinators as part of the SWCNS.

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204 The need for additional resources was identified by the WA VAD Board see *WA VADB 2021-2022 Report*, n 13, 38.

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*We have health service [VAD] Coordinators and Statewide Care Navigators. Each health service [VAD] Coordinator is like one person in a hospital. I think that the [VAD] Coordinators should be part of the Care Navigator Service that work on rotation in the various hospitals, but ultimately from the perspective of being able to provide you know backfill leave management, training support etc. should be part of the Care Navigators. [Participant 19]*

- Need for out of hours support

Multiple participants also expressed a desire for the statewide services to operate outside of business hours. It was acknowledged that while the system goal is for VAD not to be seen as an emergency service, in practice it sometimes is.

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*One of the big drawbacks [of the statewide services] is they are not available outside office hours ...that is, having someone on roster who's on duty with a phone afterhours. And surely that could be done and surely it should be done. And it won't be very expensive ... [VAD] is an emergency service, and it's really important. [Participant 14]*

*We need to talk about at some point, this perception that there are no emergencies in VAD because of course there are. [Participant 30]*

### *Issues identified*

The statewide services play a critical role in the effective functioning of WA's VAD system and are highly regarded by participants. However, some participants did raise for consideration structural questions about whether the services should be merged and whether they should be decentralised to provide a greater regional presence.

### *Recommended responses*

While it may be premature to review current structures now, future reviews should consider the current structure, processes, and resources of the statewide services to ensure they are delivering care optimally, and in a sustainable manner. Examination of other Australian models, and emerging evidence about such models, should inform any future review.

Importantly, while the authors are suggesting that these issues should formally be considered as part of future reviews, some of these suggestions could be implemented at an earlier time, if deemed appropriate. Indeed, some issues such as regional spokes could be implemented now and are already contemplated in the current Access Standard.<sup>205</sup>

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<sup>205</sup> The Access Standard provides for the development of a VAD Pharmacy Service which is required to provide services statewide "either directly from the metropolitan service or via an Authorised Supplier network of regional spoke services" see *Access Standard*, n 29, 2.

## Recommendation 22

Future reviews should consider whether the current structure, processes and resources of the statewide services are optimal for service delivery, including:

- whether greater integration of statewide services is desirable;
- whether Statewide Care Navigators should be located in regions with high VAD activity;
- whether regional hubs should be established to dispense medication; and
- whether out of hours support should be provided by the statewide services.

### 6.2 Managing VAD within a health service

The implementation of VAD within institutional settings often requires several policy decisions to be made including the level of participation in VAD and what institutional structures and policies are needed to facilitate service delivery. These decisions are generally made at the executive level (sometimes with input from staff or community).<sup>206</sup> In the context of large health services, significant resourcing is often needed to develop the necessary structures and policies to deliver VAD.<sup>207</sup>

As noted in 2.4, in the case of WA health system entities, the *Managing Voluntary Assisted Dying Policy*<sup>208</sup> requires them to have local policies and procedures in place to manage VAD processes. Outside this, however, health service providers do have discretion as to how they approach the management of VAD at a local level.

#### *Participants' submissions and evidence*

Participants identified that across the main health service providers there was variation in processes and funding, which impacted care delivery. This extended to different staffing models and funded staff allocations, as well as support for different VAD activities.

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*Although processes were set up at the start of the legislation, how things have transpired and worked in real time probably doesn't really fit with what was anticipated. I think there's some of the gaps that we all know that are there ... [We] probably need to look at some of those policies and procedures and guidelines that we have. Especially when there are multiple health sites involved and each health site ... has their own way of doing things and their own way that they want things to function. [Participant 7]*

Furthermore, participants observed that credentialing has proven to be difficult within some settings due to different approaches taken by health service providers. While some health service providers were able to expedite credentialing for practitioners for the purposes VAD, this was not widespread and very much depended on the executive.

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206 K Auret, T Pikora and K Gersbach, "Being a Safe Place: A Qualitative Study Exploring Perceptions as to How a Rural Community Hospice Could Respond to the Enactment of Voluntary Assisted Dying Legislation" (2022) 21 *BMC Palliative Care* 2.

207 Rutherford, Willmott and White, n 26, 1070.

208 *Managing VAD Policy*, n 73.

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*It's so ... hard to get GPs credentialed to come into hospital to offer this care. I mean I feel like I've literally been climbing mountains trying to get this messaging across. [Participant 33]*

### *Issues identified*

There will always be some degree of variability with respect to how health service providers deliver care. Since the legalisation of VAD in WA, each health service provider has determined their own model of care for VAD, based on a range of considerations including the resourcing available to them. This has resulted in variability of service provision, and access difficulties for some patients.

### *Recommended responses*

To enhance consistency in how VAD is provided, the DoH should consider whether further guidance should be provided about managing VAD within health services. Such guidance would ideally extend to credentialing to help promote consistency of approach.

## **6.3 VAD-IMS and mandated forms**

There are several reporting requirements imposed on practitioners who participate in the VAD process. They are required to complete forms that are provided to the VAD Board via an online information management system (VAD-IMS). Only VAD practitioners who have completed the WA VAD Approved Training are provided with a VAD-IMS account.

### *Participants' submissions and evidence*

Participants largely spoke positively about the VAD-IMS system.<sup>209</sup> Indeed, despite the administrative burden and occasional technological glitches, participants suggested that the VAD-IMS provided a sense of comfort to practitioners. Specifically, participants observed that the VAD-IMS assists practitioners to step through the process and complete the necessary steps and documentation in the correct order. This acts as assurance that they are complying with their legislative requirements.<sup>210</sup>

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*The request for the assessment process works. It works very well because we have VAD-IMS. And the confidence of Secretariat and the Board's confidence of the request and assessment process as well comes from the forced functions that exist in VAD-IMS. [Participant 21]*

Participants also identified that support provided by the VAD Board Secretariat was readily available when they encountered difficulties. However, practitioners did not always know who they should be contacting for support on different issues, and hence were, in some cases, seeking help from the wrong team (particularly in relation to VAD-IMS matters).

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209 Positive sentiments about the WA VAD-IMS system have been reported elsewhere see Haining, Willmott and White, n 4, 739; WA VAD Board, *Quality Practice Series #1* (Western Australian Government: Department of Health, January 2022) <<https://www.health.wa.gov.au/-/media/Corp/Documents/Health-for/Voluntary-assisted-dying/Quality-Practice-Series-1-Jan-2022.pdf>> (*Quality Practice Series #1*) 2.

210 Sentiments about the VAD-IMS ensuring compliance have been expressed elsewhere see BP White et al, "Prospective Oversight and Approval of Assisted Dying Cases in Victoria, Australia: a Qualitative Study of Doctors' Perspectives" (2024) 14 *BMJ Supportive and Palliative Care* e1462; Willmott et al, "Participating Doctors' Perspectives on the Regulation of Voluntary Assisted Dying in Victoria: A Qualitative Study", n 26, 127; *Quality Practice Series #1*, n 209, 2.

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*I think there is confusion from clinicians around who's who in the zoo in the roles. Because they'll [contact the Secretariat and say] I need my statement of completion to give to [my] health care service and it's like, "Oh no, no that's End of Life Care", and then they'll ask the End of Life Care team for something and then they'll ring up the Care Navigators and say, "Why can't I access VAD-IMS?" [Participant 16]*

Participants also identified other areas for improvement. In particular, participants expressed frustration with some of the forms, and highlighted that the forms had not been reviewed since the scheme began. Participants identified that some of the forms contained legalese and identified that they were challenging to navigate and complete. The layout of some of the forms resulted in some sections (such as signing) being wrongly completed, or not completed at all. Participants also suggested that some of the forms (such as the Contact Person Appointment Form) would ideally be signed earlier in the VAD process.

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*There's quite a number of issues with some of the forms. Particularly that consent form which three years down the track, I now feel like I can mostly sign it in the correct spots each time. But it does my head in every time ... Some of the forms [the issues are] just around the processes of practicality. It would be really helpful for someone to be able to print out the consent form with the filled in documentation prior to the second assessment ... So that if you're going to someone's house for the second assessment, then you can also witness the consent form on the same day without needing to find a printer at whatever time that is after that meeting. And similar with the contact person form, it'd be great to have the contact person form available before you've done some of the other stuff. [Participant 6]*

### *Issues identified*

Although the VAD-IMS is generally operating well, practitioners are still encountering some difficulties in completing forms correctly. Participants also identified some system design features which could benefit from being more streamlined (e.g. availability of particular forms at different times of the process).

### *Recommended responses*

The DoH should continue to review current reporting systems and update them as appropriate. The DoH should ensure practitioners are aware of appropriate contacts to provide support when they encounter system issues. The DoH should also consider a review of the forms to enhance useability and to reduce technical errors.

## 6.4 Information-sharing and privacy constraints

Sections 106 and 151 of the WA VAD Act restrict disclosure of personal information and information about the VAD system more generally. These restrictions aim to protect privacy and promote confidentiality with respect to a patient's medical condition and end-of-life choices. However, restrictions on information-sharing can create practical challenges. In practice, appropriate information-sharing optimises patient experience, promotes continuity of care and ensures safety. In the VAD context, restrictions placed on certain personnel accessing the VAD-IMS have the potential to disrupt patient care management.

Section 106 provides that “[A] person must not, directly or indirectly, record, use or disclose information obtained by the person because of a function that the person has, or at any time had, under this Act”. This provision applies to personal information,<sup>211</sup> but does not apply in certain cases including when the disclosure of information is “for the purpose of performing a function under [the] Act”,<sup>212</sup> or where written consent is obtained.<sup>213</sup> Failure to comply with this requirement constitutes a criminal offence.<sup>214</sup> Section 151, on the other hand, limits the extent to which the WA VAD Board can disclose information. Specifically, this section permits the disclosure of information (other than personal information) to specified persons or entities<sup>215</sup> on request.

### *Participants’ submissions and evidence*

Information-sharing and access to clinical information in the context of VAD is important to ensure the VAD process runs smoothly.<sup>216</sup> This is particularly so because people responsible for the patient's care, whether they be VAD practitioners, VAD Coordinators or statewide services' staff, often do not have a pre-existing therapeutic relationship with the patient. Also, in many VAD cases, there is a need for care coordination within a particular care setting, and sometimes between care settings (e.g. if a patient is transferred from a residential facility to a hospital setting). Access to information about VAD is also important in the context of quality improvement and targeted education.

- Restrictions on VAD-IMS access

Some participants whose role was to support a patient to access VAD experienced challenges accessing relevant information. In particular, participants identified the inability of the SWCNS and VAD Coordinators to access information in the VAD-IMS.<sup>217</sup> Participants advised that such access would have been useful, for example, to contact individuals who lodged a first request (and who may require further support in connecting to a VAD practitioner), or more generally to assist a patient with their VAD care coordination. Some participants suggested that the inability to access the VAD-IMS was due to certain personnel not being explicitly recognised under the WA VAD Act. Some noted that other jurisdictions (e.g. Queensland) permitted their equivalent care coordination staff to access their online portal.

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211 *Voluntary Assisted Dying Act 2019* (WA) s 106(3).

212 The authors note that the WA VAD Act does not include detail about who is considered a person performing a function under the Act. At the time of writing, no specific guidance on this or section 106 in general is available on the WA DoH website.

213 *Voluntary Assisted Dying Act 2019* (WA) ss 106(2)(a), 106(2)(f). The authors note that section 106(2) also lists other exceptions.

214 The maximum penalty for this provision is 12 months' imprisonment. See *Voluntary Assisted Dying Act 2019* (WA) s 106(1).

215 This includes a public authority as defined in section 6 of the *Health Services Act 2016* (WA), or a person or body for the purposes of education or research. See *Voluntary Assisted Dying Act 2019* (WA) s 151.

216 Go Gentle Australia, “It's a New System and There are Still Some Challenges”, n 144.

217 The 2022-2023 WA VAD Board Annual Report similarly identified a need to permit information to be shared with people who are critical to the delivery of VAD such as the SWCNS and VAD Coordinators. The WA VAD Board recommended for the WA VAD Act to be amended so such personnel were designated a function under the Act, see *WA VADB 2022-2023 Report*, n 13, 56.



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*We have the Care Navigator service that plays ... probably besides from an individual VAD practitioner the most pivotal role in the process, and they are an entity that cannot be replicated ... [but they] that don't have a function under our legislation. The Board ... can share information that they access through their performance of their functions under the Act for the purpose of performing a function ... [The way] VAD-IMS was established was that information is only shared with people through our VAD-IMS for people that are performing functions ... [So] having a system that [recognises their role] ... would facilitate improved information sharing ... There could be changes to the way that the legislation is actually written, that actually would support the Board in transferring ... mandatory movement of personal information without having to seek consent. [Participant 19]*

It was also noted that the SWCNS and VAD Coordinators were often the first port of call to support practitioners needing assistance with the VAD-IMS. The inability to access the system restricted their ability to provide practitioners with troubleshooting support.

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*[The SWCNS and VAD Coordinators] are often the point of first call from practitioners who are struggling, particularly new practitioners or those that don't see patients often. So, [practitioners] forget that [the SWCNS and VAD Coordinators] don't actually have access to the IMS system to know how to navigate it and guide them. [Participant 5]*

Frustration was also expressed by participants in relation to the inability of nurse practitioners, who were acting as administering practitioners, to access the VAD-IMS for purposes of accessing clinical information about their patients (including previous VAD assessments).

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*[The nurse practitioner role is limited to] the very end and it can be where a practitioner is overseas or not available to do the admin and then [the nurse practitioner] get[s] asked the day before or two days before, "Quick, this person needs admin in two days' time, or tomorrow can you do it?" [Without] getting a handover, knowing what's wrong with the patient. [They] might be told the person's got breast cancer, but ... know nothing else about that patient ... it would be helpful [for] nurse practitioners just to be able to see those assessments and just get a bit of background information on the patient. [Participant 29]*

One participant, while conceding these challenges, did emphasise that the VAD-IMS was designed to promote compliance with the Act rather than serve as a digital medical record.

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*The Act is very prescriptive, and the steps of VAD-IMS follow that. But the expectation from clinicians is it's actually part of a medical record ... That wasn't the intention when it was set up, but I think that's how clinicians see it. They see it as the patient's medical record for VAD. [Participant 16]*

- Challenges of managing VAD patients within a care setting due to disclosure and documentation restrictions

Section 106 was also thought to raise challenges for documentation practices and information-sharing within particular settings. Some participants suggested there was a degree of uncertainty about whether information about VAD could be lawfully included within a medical record. This lack of clarity was thought to introduce a degree of vulnerability and anxiety for those working in the field and was considered particularly impractical within the health service provider setting.<sup>218</sup>

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*The absolute opposing situation of a tertiary multidisciplinary setting where practitioners and those of us that are having conversations that are required to document something and not allowed to give away any information about it. It's nonsensical and has been difficult to get clarity from the Department and legal people ... We know in every other sphere of medicine that good collaborative multidisciplinary care keeps people safe and delivers better outcomes. I think there needs to be some clarification around that. [Participant 5]*

Participants noted that the restrictions did not apply when the patient provided written consent. However, they commented on the impracticality of routinely seeking patient's written consent to record clinical information.

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*And that amongst us all we can ask, "Are you involved with this? What have you done so far? Where are things up to?" Sometimes when a patient – I can't get access to the patient to get that written consent to then have the conversation. It just gets in the way of smooth, streamlined care. [Participant 5]*

Participants also identified as challenging the inability to share information with certain personnel directly involved in caring for the patient.

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*In regards to ... Section 106 ... we have been so working hard at integration into the hospital system ... How does that work in a hospital ward setting when this is stuff that the rest of the ward needs to know? But I'm technically not supposed to share, but also, we're trying to make this part of usual care. ... We used to joke about it that we would – especially early days – it'd be like secret squirrel, no one knows anything about it. It's totally confidential. Then the patient [is] in Room 3 and every time the cleaner goes in or the person [is] asking [them] what they want for dinner, the first thing the patient says is, "I don't need dinner because I'm doing VAD tomorrow". [Participant 6]*

Complexities were also observed regarding the lack of knowledge about the patient's decision to access VAD by some staff not directly involved in the patient's medical care. However, restriction on information-sharing in relation to these personnel seemed to be more palatable to participants.

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218 At the time of writing, further guidance about section 106 is not available on the WA DoH website.

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Staff were really challenged by, “There’s something going on here and I don’t know about it, and I can see a group of my teammates crying”, on the day when the administration occurred. So that was a challenge around then having conversations with the staff who didn’t know to say, “Look, something has occurred, and yes, people are upset, but they are being supported and for reasons of privacy, I can’t and won’t be telling you what’s going on”. [Participant 37]

- Restrictions placed on the ability of the WA VAD Board to proactively release information

A final and specific issue raised by participants relates to the restrictions imposed by section 151. This provision allows the WA VAD Board to release information for the purpose of education or research. However, release of information is only allowed “on request”. This provision was thought to limit the ability of the Board to proactively release information when it considered it appropriate to do so.

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The Board currently can release information for education and research on request ... this creates some issues where the Board is the holder of all information, and they might also then identify ... education needs ... I think they would very much like to be able to proactively use the information that they hold to educate ... if they’re going to undertake their monitoring function and go and meet with people to make sure the Act is running OK ... In reality, there might be an educative component to that as well ... [It’s just stupid to say, “We’re coming to see you and you want the Board to come and talk to you, can you request this information we’d like to tell you about?”] [Participant 19]

### *Issues identified*

Current practices and restrictions in relation to information-sharing have negatively affected the ability of VAD practitioners and other VAD staff (e.g. the SWCNS and VAD Coordinators) to deliver appropriate care to patients.

Current restrictions also have the potential to make information sharing by the Board, in the process of carrying out its functions, unnecessarily complex.

### *Recommended responses*

System modification is needed to ensure those who have a direct role in supporting VAD access for a patient can carry out their functions effectively. This could be achieved through legislative amendment or through clearer guidance on what is currently permissible and ways in which information-sharing practices can become more streamlined.

To effectively and efficiently carry out its functions, the Board should have the ability to disclose relevant information without first receiving a specific request to do so. Changes to legislation and/or practice should be considered to facilitate this.

## Recommendation 23

Consider strategies such as legislative amendment or modification of system design to permit individuals who are fulfilling a role under the Act to have access to the information needed to undertake that role.

This would include:

- access to clinical information and medical records (which may include information about VAD) needed to assess eligibility or support a patient's VAD process; and
- access (including for the SWCNS, VAD Coordinators and nurse practitioners acting as administering practitioners) to the VAD-IMS as needed to support a patient's VAD application.

## Recommendation 24

Consider changes needed to legislation and/or practice to ensure the WA VAD Board can use information it receives to effectively and efficiently carry out its functions.

### 6.5 Relationship between VAD and palliative care

VAD is a new end-of-life choice. To date, the extent to which VAD has been integrated within end-of-life care and palliative care varies across the state. Some in the palliative care community remain opposed to VAD on the basis that VAD is incompatible with palliative care philosophies.<sup>219</sup> But others in the palliative care workforce support VAD choice and advocate for both forms of care to co-exist. There are also mixed views about whether VAD should be formally incorporated within palliative care or remain distinct.<sup>220</sup> The WA Board's reports indicate that most people electing to access VAD also access palliative care concurrently.<sup>221</sup> However, participants noted that very few palliative care specialists were trained VAD practitioners.

#### *Participants' submissions and evidence*

Participants shared mixed experiences regarding interaction with palliative care. On the positive side, there were reports of VAD and palliative care services in some institutions operating in parallel. Some palliative care staff supported patients accessing VAD even if they personally (or their institution) did not support VAD in principle. Such experiences provided comfort to patients and facilitated continuity of care. VAD practitioners also felt that the support from palliative care colleagues was critical to their ability to carry out their work.

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219 For reflections on the current tensions between palliative care and VAD and calls for it to be more streamlined see, for example, McLaren and Mewett, n 30, 116; Rutherford, Willmott and White, n 26, 1069; *Conference Report: VAD CON 2023*, n 23, 7; Go Gentle Australia, "It's a New System and There are Still some Challenges", n 144; *This is My Stop: Lisa's Story*, n 13; *This is My Stop: Sam's Story*, n 15.

220 For different views about the relationship between VAD and palliative care see, for example, K Auret et al, "'Respecting Our Patients' Choices': Making the Organizational Decision to Participate in Voluntary Assisted Provision: Findings from Semi-structured Interviews with a Rural Community Hospice Board of Management" 21(1) *BMC Palliative Care* 161, 5; SM Blaschke et al, Common Dedication to Facilitating Good Dying Experiences: Qualitative Study of End-of-Life Care Professionals' Attitudes Towards Voluntary Assisted Dying" (2019) 33(6) *Palliative Medicine* 562; S Booth, P Eleftheriou and C Moody, "Implementing Voluntary Assisted Dying in a Major Public Health Service" (2021) 214(8) *Medical Journal of Australia* 343, 346; CM Haining, LA Keogh and LH Gillam, "Understanding the Reasons Behind Healthcare Providers' Conscientious Objection to Voluntary Assisted Dying in Victoria, Australia" (2021) 18 *Journal of Bioethical Inquiry* 277; J Phillip, "Palliative Care Physicians' Preparation and Planning for the Implementation of the Voluntary Assisted Dying Act in Victoria" (2021) 51(10) *Internal Medicine Journal* 1559; Rutherford, n 30; Rutherford, Willmott and White, n 26, 1069; E Waran and L William, "Navigating the Complexities of Voluntary Assisted Dying in Palliative Care" (2020) 213(5) *Medical Journal of Australia* 204; Go Gentle Australia, "It's a New System and There are Still some Challenges", n 144.

221 *WA VADB 2021-2022 Report*, n 13, 20; *WA VADB 2022-2023 Report*, n 13, 23. For reflections on pursuing palliative care alongside VAD in the WA context see Go Gentle Australia, "It's a New System and There are Still some Challenges", n 144; *This is My Stop: Dr Gareth*, n 15; *This is My Stop: Lisa's Story*, n 13; *This is My Stop: Care Navigator Nikki*, n 157; *This is My Stop: Sam's Story*, n 15.

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*I think that they co-exist well. I think that what needs to happen is very clear communication between the patient and their doctor and the clinical team about what the expectations are in terms of timelines ... But, really, what I would say about palliative care and VAD is that conversations about symptom control are imperative and keep going all the way along the VAD journey. [Participant 36]*

*I was actually thinking what's working well is the relationships are better than I expected them to be three years down the track. From a hospital perspective, palliative care generally it hasn't all fallen apart ... I think that real sense of trying to build respect and relationships has been a good approach. [Participant 6]*

However, negative encounters were also experienced by stakeholders, with participants commenting that the absence of support from palliative care staff made the delivery of VAD challenging. Many participants observed the inability of patients to access VAD if they were receiving palliative care in religiously-affiliated institutions. Further, participants commented that there were many strong personalities in palliative care and their staunch opposition to VAD has led to hostile encounters between palliative care and VAD staff, as well as hostile behaviours towards patients and their families. Participants reported conduct including abandoning patients, withdrawing palliative treatment, condemnation and rudeness to patients seeking VAD. It has also resulted in VAD practitioners' eligibility assessments being challenged, and refusal of hospice care.

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*I think it's an institution by institution thing, and an individual by individual thing ... I have had pushback by ... [palliative care] colleagues in the state ... I can only talk for hospitals in my region, but the big hospital in my area is run by a service is that so fearful of VAD that it rolls over into their professionalism. It's no longer patient-centred. It's their centred. And it is extremely bad, is all I can say ... [T]hat palliative care service has impacted the delivery, even the rolling out of FTE which finally came. And they're impacting clinics being set up because they don't [do VAD] under the palliative care tier of clinics. [Participant 28]*

In other cases, opposition to VAD manifested more subtly. For example, participants reported that palliative care staff provided false hope and promises that the patient's suffering would be alleviated once medication is re-titrated to deter patients from pursuing VAD. In some cases, patients decided to abandon the VAD process, because they perceived they would receive sub-optimal care if transferred to another institution (e.g. public hospital) to receive VAD.

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*I think they did like make a few false promises ... And I think there was a lot of time wasted with [Specialist Palliative Care Service] promising once we change this or re-titrate this medication things would be better. And like, it never got better. [Participant 2]*

*[The patient's] three nights in [the Public Metropolitan Hospital] was so horrendous in a group room of four people, there's no way I wanted him back at that Public Hospital. It wasn't an acceptable place to be, except for a consultation ... And it's not their fault, the public system is overloaded. He wouldn't have got even the care that he did get ... Going to [the Public Metropolitan Hospital], was an option for VAD to occur, but it wasn't an option for [the patient]'s quality of life to go back to a ward there. [Participant 35]*

### *Issues identified*

Despite some pockets where VAD and palliative care practitioners are working well together, there is evidence that, in some settings in WA, this is not occurring and this can affect the quality of patient care.

### *Recommended responses*

While there is some evidence internationally that, over time, VAD can successfully exist in tandem with palliative care,<sup>222</sup> the DoH may wish to consider steps to engage leaders in the palliative care and VAD fields to collaboratively expedite this cultural change.

## **6.6 Structure and interaction between Department of Health, VAD Board and VAD Board Secretariat**

The WA VAD Board is an independent body created by the WA VAD Act.<sup>223</sup> It has a range of functions set out in the legislation including monitoring the operation of VAD within WA.<sup>224</sup> The Board is supported in its functions by a Secretariat which is staffed by DoH employees. The DoH's End of Life Care Program also has carriage of the delivery of VAD (e.g. through managing the practitioner verification process, developing resources, contract management for statewide services and the WA VAD Approved Training).<sup>225</sup> All of these bodies work together to deliver VAD in WA.

### *Participants' submissions and evidence*

Only a limited number of participants raised existing structure as an issue to be addressed. Participants noted complexities in the current structure of the VAD Board, the Secretariat, and the DoH's End of Life Care Program team. Participants also questioned whether the Board could carry out its functions effectively and independently when supported by a Secretariat that is staffed by employees from the DoH and emphasised the need for the Secretariat to work in a confidential environment.

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*[Having the] Secretariat in the confidential environment within the Health Department is critical – is really important ... it [has been] about those relationships. And this whole notion that [you] have to build relationships with these people, I get it, but that's not the reality of the bureaucracy. So how does the bureaucracy work to support an independent Board and a Secretariat and all the other components that [are] operating within? [Participant 25]*

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222 See, for example, SM Gerson et al, "The Relationship of Palliative Care with Assisted Dying is Lawful: A Systematic Scoping Review of the Literature" (2020) 59(6) *Journal of Pain and Symptom Management* 1287. Similarly, in a report commissioned by Palliative Care Australia it was noted that, "[i]f anything, in jurisdictions where assisted dying is available, the palliative care sector has further advanced" see Palliative Care Australia, *Experience Internationally of the Legalisation of Assisted Dying on the Palliative Care: Final Report* (Aspex Consulting, 28 October 2018) 5.

223 *Voluntary Assisted Dying Act 2019* (WA) s 116.

224 *Voluntary Assisted Dying Act 2019* (WA) s 118.

225 *WA VADB 2022-2023 Report*, n 13, 42.

Some participants also raised concerns about the ability of the Board to carry out its functions without a dedicated budget (that was subject to its control) or independent advice.

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*The Board is independent ... [but] they get their support through the Department ... I think realistically the Board would probably prefer the independent legal advice to the Department, because ... [the] legal advice [they get] from the Department is protecting the Department, not necessarily protecting voluntary assisted dying. [Participant 19]*

However, a subset of participants considered that despite potential structural issues, in practice, the current approach was working. Many of these participants thought this was due to the specific personnel currently in these roles and the relationships fostered. Participants surmised that any changes to such personnel in the future had the potential to create risk that the system might not function in the same positive way.

### *Issue identified*

The ability for the VAD Board to maintain independence and carry out its legislative functions is a critical safeguard of the WA VAD system. Yet the current structure creates potential tensions for this independence.

### *Recommended response*

The authors recommend, for future consideration, that the current VAD oversight structure (Board, Secretariat and DoH) be reviewed to determine whether this is the optimal oversight structure to enable the Board to perform its legislative functions.

## **Recommendation 25**

**Future reviews should consider the optimal VAD oversight structure, including that which supports the VAD Board to operate independently and carry out its functions.**







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