

Policy Document

Voluntary Assisted Dying (2022)

Position Statement

AMSA believes that Voluntary Assisted Dying (VAD) legislation should:

1. Ensure VAD services are widely and equally available to all people wishing to access them;
2. Include eligibility criteria that is non-discriminatory towards individuals seeking VAD, and has an appreciation of the subjective nature of intolerable suffering;
3. Enforce adequate safeguards that appropriately balance protection of vulnerable populations and respecting autonomous self-determination at the end of life;
4. Ensure the conscientious objection of individual medical practitioners or health care services does not limit a person's access to VAD and quality end-of-life care;
5. Ensure medical practitioners involved in VAD receive adequate education and clinical training alongside necessary supports to enable them to sustainably deliver VAD services;
6. Ensure medical students receive appropriate education surrounding VAD and their legal and ethical obligations, as well as the core principles necessary for safe and quality VAD care;
7. Ensure that the consideration of VAD is not seen as an alternative to appropriate palliative treatment, instead occurs alongside high quality palliative care. Ensure that the consideration of VAD is not seen as an alternative to appropriate palliative care and does not interfere with other palliative treatment;
8. Maintain high quality, accessible palliative care services as an essential component of end of life care;
9. Actively involve medical professionals (including but not limited to palliative care specialists) in the design and adoption of any VAD legislation.

Policy

AMSA calls upon:

1. The Federal Government to:
 - a. Repeal the *Euthanasia Laws Act 1997* (Cth); thereby giving Australian territories the right to debate and legislate voluntary assisted dying laws;



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- b. Amend sections 474.29A and 474.29B of the *Commonwealth Criminal Code Act 1995* (Cth) to explicitly preclude its applicability to VAD laws; thereby giving medical practitioners the confidence to use Telehealth; and
- c. Review the range of services eligible under the Medicare Benefits Schedule in relation to VAD to ensure that practitioners are being adequately reimbursed for their coordination of VAD.

2. State governments to:

- a. Ensure VAD legislation encompasses appropriate safeguards that are viable, practical, and are the least restrictive;
 - i. By allowing medical practitioners the freedom to raise VAD as an option in end-of-life care discussions;
 - ii. By offering self and practitioner administration as equally viable options;
 - iii. By allowing VAD substances to be provided at a regional or rural pharmacy and allow flexibility in the delivery of the prescription from doctors;
 - iv. Considering changing the eligibility requirement for people to be expected to die in the 6 and 12 month prognostic timeline;
- b. Ensure any VAD legislation and its statutory obligations are evidence-based, taking into consideration data and perspectives from overseas jurisdictions where this is legal;
- c. Protect vulnerable people, through a series of rigorous safeguards, so that any access to VAD is strictly limited to the intended population;
- d. Consult stakeholders and interest groups advocating and protecting the rights of all people, particularly those it disproportionately impacts;
 - i. By providing funding to support the participation of Aboriginal and Torres Strait Islander health care workers within the Statewide Care Navigator Service and participating practitioners;
 - ii. By Liaising with Aboriginal and Torres Strait Islander elders and community members about how to provide culturally safe care in relation to VAD;
 - iii. By ensuring that VAD legislation is accessible to people with limited proficiency in English;
 - iv. By respecting the capacity of people with a disability and/ or mental illness;
- e. Ensure legal protections exist to uphold the right for medical professionals to conscientiously object whilst respecting a patient's right to access VAD care;
- f. Distinguish between conscientious and 'non-conscientious' objection to VAD;

- g. Endorse telehealth as an appropriate method to facilitate VAD consultations with patients.
 - h. Provide comprehensive guidelines that inform the application of VAD legislation in the clinical environment, and help guide organisations and individual practitioners to adopt and implement VAD care as an accepted evidence-based care model in their practices;
 - i. Fund further research into the implementation of VAD to investigate and improve:
 - i. Equitable access for all eligible people;
 - ii. Participation in VAD training;
 - iii. Psychological support for practitioners;
 - j. Consider the use of an Advance Care Directive in unique cases where decision-making capacity is fluctuating or deteriorating, in order to:
 - i. Preserve the VAD process in the circumstance of transient loss of decision making capacity which is subsequently regained;
 - ii. Carry out an individual's completed VAD request to entirety in the circumstance of deteriorating decision making capacity (DMC), provided the patient has consistently demonstrated DMC throughout the VAD process;
 - k. Engage in collaboration and consultation with other participating states to improve VAD legislation;
 - l. Actively engage medical professionals (including but not limited to palliative care specialists) in the designing of any VAD legislation;
 - m. Ensure the views of the general public and practitioners remain central to the VAD debate and any relevant legislation; and
 - n. Ensure funding towards end-of-life care includes both VAD and palliative care services and that VAD funding does not reduce palliative care funding.
3. Voluntary Assisted Dying Review Boards in all participating states to:
- a. Include data in annual reports that provide a comprehensive review of the VAD process, including specific reasons for withdrawal, and, in the case of withdrawal due to death or loss of decision making capacity:
 - i. The stage of VAD process they had progressed up to;
 - ii. The duration of days into the process they were;
 - iii. Any other barriers that delayed the process.
4. Medical Deans Australia and New Zealand (MDANZ) to:
- a. To ensure medical curriculums increasingly incorporate education around VAD into clinical and didactic teaching, so that medical students are appropriately educated and trained on VAD implementation, including, but not limited to:

- i. How to respond to a request for VAD within the students' scope of practice;
 - ii. Familiarise students with all aspects of the VAD process and relevant members of the multidisciplinary team;
 - iii. Communicate appropriately with patients, their family, and medical practitioners about VAD.
- 5. Health care services to:
 - a. Ensure access to VAD is not impeded by:
 - i. Providing high quality of care through facilities and well-trained staff;
 - ii. If following Pathway B or C of the 'model of care pathways,' ensure timely transfer of care to relevant participating facilities;
 - b. Respect patients' wishes to access VAD free from discrimination; and
 - c. Respect doctors and staff choosing to participate in VAD without judgement.
 - d. Ensure that VAD education, workshops and protocols are adequately integrated into institutional policy in line with relevant legislation and community expectations.
- 6. Medical professionals to:
 - a. Ensure patients are fully informed about all treatment options in end-of-life care discussions within the boundaries of state law;
 - b. Be a patient advocate, including referral to another practitioner in the event of conscientious objection;
 - c. Not discriminate against patients seeking VAD, or against doctors who choose to perform VAD related services; and
 - d. Continue to engage in public discourse surrounding improving VAD provision and actively engage in policy consultation processes.
 - e. Use telehealth for VAD consultations.
- 7. Speciality medical colleges and other governing bodies involved in the training of health professionals involved in end-of-life care to:
 - a. Continue to provide high quality training and support surrounding end of life care for training and member medical professionals;
 - b. Provide appropriate information on VAD legislation to physicians involved in these services;
 - c. Not discriminate against medical professionals based on their stance regarding VAD;
 - d. Provide expert opinion where appropriate to the national debate surrounding VAD and end-of-life care;
 - e. Ensure all medical practitioners are exposed to all VAD legislation during their training and are made aware of their rights, obligations and choices regarding VAD; and

- f. Advocate for appropriate remuneration and support for the training and processes involved in the provision of VAD, including, but not limited to:
 - i. Psychological support for medical practitioners involved in VAD;
 - ii. Adequately reimbursing medical practitioners for the time involved in supporting a person through the VAD process but not incentivising or providing financial award for participating in VAD.

- 8. Medical Board of Australia to:
 - a. Provide specific guidelines for participating medical practitioners in assessing decision making capacity in relation to VAD, including, but not limited to:
 - i. Clarity on the presumption of capacity;
 - ii. Whether people are required to meet a higher standard of capacity compared to any other healthcare decision.

Background

The Australian Medical Students' Association (AMSA) is the peak representative body for Australia's medical students. Australia's implemented and expected voluntary assisted dying (VAD) laws represent a paradigm shift in Australian medical practice. AMSA believes that under a safe legal framework, VAD extends the right to self-determination at the end of life. However, AMSA acknowledges the importance of reviewing VAD to ensure its safeguards are operating as intended. As such, AMSA advocates for legislation that protects vulnerable populations without limiting accessibility. Accordingly, AMSA calls for the improved support of medical professionals involved in VAD, including, but not limited to, further education, training, and self-care.

Definitions

Euthanasia

Euthanasia describes the practice of intentionally ending a life to relieve suffering [1]. Euthanasia may be active: a deliberate act undertaken to end a patient's life, or passive: the omission of an action which would reasonably be expected to keep the patient alive. Parliamentary rejection of 'euthanasia' in favour of 'voluntary assisted dying' has shifted the emphasis from a paternal practitioner-centric approach to a more autonomous patient-centred approach over death [2].

Voluntary Assisted Dying

Voluntary assisted dying (VAD) is the end-of-life care practice adopted by Australian jurisdictions and chosen for its emphasis on the patient's choice to exercise autonomy [3]. Victoria's *Voluntary Assisted Dying Bill 2017* defines VAD as the "administration of a voluntary assisted dying substance and includes steps reasonably related to such administration." [4] This definition is consistent, if not exact, with legislation enacted by the other states [5]. Parliament explicitly states

that VAD is not interchangeable with euthanasia and suicide as it is about assisting a person who is already dying [2]. A person who dies by VAD is considered to have died secondary to the disease, illness, or medical condition from which they suffered, rather than by suicide [6].

Safeguards

Safeguards refer to any measures that are in place to ensure that the intention behind VAD legislation is properly implemented. Safeguards govern each step of the process and are designed to protect both the potentially vulnerable people requesting VAD and the health practitioners delivering VAD services [7].

While an in-depth discussion of safeguards is beyond the scope of this policy, a few examples are included from Victoria's Voluntary Assisted Dying Bill 2017 that are common to all Acts [4,5].

1. The person must make the request personally
2. The person must be diagnosed with a disease, illness or medical condition that is expected to cause death within weeks or months, not exceeding 6 months
3. The person must be assessed by two separate independent medical practitioners.

Voluntary Assisted Dying in Australia

Background of Law Reform

Legalising VAD in Australia has been a lengthy and turbulent road spanning over three decades. By the end of 2015 for example, a total of 51 bills addressing VAD had been introduced to Parliament across Australia [8]. In 1995, the Northern Territory enacted the *Rights of the Terminally Ill Act 1995* (NT), becoming the first jurisdiction to allow terminally ill patients to end their life [9]. However, this Act was overturned in 1997 when the Commonwealth Government passed the *Euthanasia Laws Act 1997* (Cth) prohibiting the Territories' right to legislate or debate voluntary assisted dying laws [10].

In 2015, the Legislative Council in Victoria commissioned an inquiry and expert panel providing recommendations on end-of-life care choices. Of the 49 recommendations, legalising VAD was one of them. Thus, Victoria became the first state to legalise VAD, after enacting the *Voluntary Assisted Dying Act 2017* (Vic) which came into effect on 19 June 2019. It has been cited as the safest and most conservative model worldwide, with 68 safeguards to protect vulnerable Victorians from exploitation and coercion [11]. The Western Australian Parliament then took the opportunity to analyse Victoria's implementation of VAD, and assess how the Victorian model may operate within Western Australia [12]. On 10 December 2019, Western Australia followed Victoria in passing the *Voluntary Assisted Dying Act 2019* (WA), which came into operation in July 2021. WA's Act is mostly consistent with that of Victoria, with adjustments to better reflect the unique requirements of West Australians, such as geographical challenges[12]. Both states had an 18 month gap between the time the Acts were passed to the time the Acts were

operational. This time was crucial for medical institutions and participating medical practitioners to undergo training and for policy development.

VAD Legislation in Australian States

In March 2021, the Tasmanian Parliament passed the *End-of-Life Choices Act 2021*. Expected to commence in October 2022 following an implementation period, the Act legislates the provision and regulation of VAD within Tasmania. The Act established the VAD Commission to operate as the VAD regulatory body under the Minister for Health [13]. Furthermore, a Voluntary Assisted Dying Navigation Service, will be functioning by mid-2022 to assist patients, healthcare providers and services in processes surrounding access and provision of VAD [14].

South Australian Parliament passed the Voluntary Assisted Dying Act 2021 in June 2021. This Act is likely to commence by early 2023 after an implementation period. Implementation will be governed by the Voluntary Assisted Dying Implementation Taskforce, supported by five Working Groups and an Implementation Taskforce. The Voluntary Assisted Dying Review Board will monitor VAD practice in compliance with the Act [15].

In September 2021, the Queensland Parliament passed the *Voluntary Assisted Dying Act 2021* [16]. This Act will commence in January 2023 after an implementation period. A Statewide Care Navigator Service and Statewide Pharmacy Service will assist patients and health practitioners with the process and ensure safe provision of the VAD substance respectively. The Voluntary Assisted Dying Review Board will also be established to monitor VAD [16].

In November 2021, the *Voluntary Assisted Dying 2021* Bill passed in the New South Wales Parliament House of Representatives [17]. The Bill was introduced to the Upper House in February 2022, where it is currently being debated [17]. This Bill involves the establishment of The Voluntary Assisted Dying Board, which must be notified when a patient makes a request, and will oversee the VAD process [18].

Implementation in Victoria and WA

In Victoria, VAD is now entering its third year, meaning that the Voluntary Assisted Dying Review Board will now transition from half-yearly to annual reports. The latest report in June 2021 reports that to date, of the 836 people who were assessed for eligibility, 807 were eligible. Of those people, 712 had a consulting assessment, with 700 assessed as eligible. 674 people went on to apply for a permit, and 597 permits were issued (12% practitioner-administered and 88% self-administered). However, only 331 people have died from taking the prescribed medication. Overall, there were 342 cases withdrawn. This figure is not stratified any further; combined reasons include 'administrative errors, applicants discontinuing the process or died before the process was complete.' There are 234 medical practitioners trained and registered in the portal, an increase of 11% since the commencement of VAD [19].



In Western Australia, VAD is still within its first year. The Voluntary Assisted Dying Board is yet to publish a report, however, the Minister for Health provided an update in November 2021. During the first four months, there were 125 completed first assessments and 50 VAD deaths. There were only 43 medical practitioners who have completed the approved training, with 169 registered for training [20].

Eligibility Criteria

To ensure safety, VAD legislation must strike a balance between promoting patient autonomy through accessibility and restricting its availability. A person may access VAD, provided they have been deemed eligible by both the coordinating and consulting practitioners [21]. Eligibility criteria for accessing VAD remains largely the same across Australian states. The following examples are only a sample of the points with consistent meaning across each state. A person will be eligible for VAD if they [4,5]:

- are aged 18 years or more;
- an Australian citizen or permanent resident;
- are ordinarily a resident in that state, and has been a resident in that state for at least 12 months at the time of making a first request;*
- has decision-making capacity (discussed in *Decision-Making Capacity*)
- acting voluntarily and without coercion;
- is diagnosed with a disease, illness, or medical condition that is:
 - incurable;†
 - advanced, progressive, and will cause death;
 - expected to cause death within six months (12 months in the case of neurodegenerative conditions), and;
 - causing suffering that cannot be relieved in a manner the person finds tolerable.‡

*Queensland and Tasmania also grant eligibility to people who have ordinarily been a resident in Australia for 3 years.

†Incurable is not used in the WA or Queensland legislation.

‡Intolerable suffering is used in Queensland and Tasmanian legislation.

The subjective nature of the terms ‘suffering’ and ‘tolerable,’ with suffering broadly encompassing physical pain as well as psychological, social, spiritual, or existential pain, makes these terms difficult to measure in an objectively consistent way [24]. If a practitioner has trouble assessing any of the eligibility criteria, VAD legislation mandates that the patient be referred to a practitioner with the appropriate skills and training [25]. It is important to note the Queensland *Voluntary Assisted Dying Act 2021* provides for an exemption to the residency rule, given a person has a substantial connection to that state and there are compassionate grounds for granting the exemption [5].

Steps of the VAD Process

A person must make a first request for VAD to a medical practitioner, if that practitioner accepts, they become the coordinating practitioner (or primary

medical practitioner in Tasmania). The coordinating practitioner assesses the eligibility of the person and if satisfied, submits a report to the Board and refers the person for a second assessment by a consulting practitioner. A report of this second assessment is also provided to the Board and coordinating practitioner. If assessed as eligible by both doctors, the person can continue the process by making a written declaration requesting access to VAD in the presence of two eligible witnesses, who both sign the form. Following this, the person can make a final request and appoints a contact person, someone who returns the unused VAD substance to a pharmacy. The coordinating practitioner conducts a final review of all stages so far and provides this review to the Board. The prescribing coordinating practitioner and dispensing pharmacist must provide certain information to the person relating to administration. The pharmacist also submits a dispensing form to the Board. The person may then access VAD through self or practitioner administration. Safeguards require an eligible witness to be present for practitioner administration. The person is able to stop the process at any point [4].

To act as coordinating or consulting practitioners, medical practitioners must have completed mandatory VAD training and fulfil other eligibility criteria, which differ between states. Victoria requires that either the coordinating or consulting practitioner has practised for at least 5 years after completing a fellowship with a specialist medical college or vocational registration. WA only requires 1 year to be eligible and lacks the stipulation for either practitioner to have expertise or experience in the disease, illness, or medical condition of the person being assessed [4, 24]

Decision-Making Capacity

Assessing DMC

Decision-making capacity (DMC) or capacity is a legal requirement describing a person's ability to make a decision. DMC is an essential component of informed consent and is enshrined within the ethical principle of autonomy [25]. The focus of assessing DMC is not whether the patient's decision is right or wrong, but to determine whether they can apply relevant information to make a decision that is consistent with their long-held preferences and values [26]. In relation to VAD legislation, a person has DMC if an assessment concludes they can [4]:

1. Understand the information relevant to the decision relating to access to voluntary assisted dying and the effect of the decision.
2. Retain that information to the extent necessary to make the decision.
3. Use or weigh that information as part of the process of making the decision.
4. Communicate the decision and the person's views and needs as to the decision in some way, including by speech, gestures, or other means.

Safeguards mandate that DMC must be maintained or 'endured' for the entirety of the VAD process [4]. Unless doubt is raised, a person is presumed to have DMC [4]. Due to the irreversibility and gravity of the decision, a higher standard of

competence must be demonstrated to ascribe DMC to the patient, as with all end-of-life care decisions [21, 27]. Thus, like the other eligibility requirements, assessing capacity in relation to VAD necessitates the use of two independent medical practitioners and referral to a professional with appropriate skills and training when faced with uncertainty [23]. The same applies if the coordinating practitioner is unable to assess voluntariness and lack of coercion [21, 27]. Like capacity, safeguards mandate that for a person to continue through the VAD process, their decisions must be voluntary and free of coercion, this is important in protecting people from undue influence or abuse [27]. Despite being distinctly different legal topics, testing for undue influence at the same time of a capacity assessment is an endorsed approach to VAD and the model currently in use [27].

VAD laws allow for supported decision-making (SDM) but its application in the context of VAD should be approached cautiously [27,28]. No person can be ascribed as lacking capacity if they have not been given adequate information to consider, or support for communicating their decision [27]. However, allowing someone to communicate or assist with communicating another person's decision raises concerns about potential undue influence, especially given the gravity of VAD decisions [27]. While current legislation recognises the key role of approved assessment training, there remains evidence of knowledge gaps in practitioners' understanding of assessing capacity [27,28]. Anecdotally, many doctors report a low confidence and skills in assessing capacity [27,28]. A lack of knowledge and confidence affects both patients and health practitioners, as it leaves doctors unprepared to manage discussions regarding VAD. Surveys on the attitudes of Australian and New Zealand geriatricians and oncologists also emphasised desire for greater certainty regarding boundaries of decision-making capacity and eligibility [28].

Disability & Mental Illness

Across all VAD Acts, disability and mental illness alone do not preclude a person from accessing VAD if all other eligibility criteria are met [29]. However, people with disability or mental illness may be unfairly predisposed to ineligibility as a result of the poorer quality of care associated with implicit biases present in many clinicians [30]. This is particularly threatening to patients where incapacity may be paternalistically assumed in favour of a DMC assessment or the chance for SDM [31]. The right to the latter is required by VAD legislation, which recognises that a person is still said to have capacity if they can make a decision with 'practicable and appropriate support' [27]. Some examples given within the Act include "giving a person additional time" and "assisting a person to communicate the person's decision" [4]. While SDM helps to realise the capacity of people with disabilities, its relatively recent introduction into clinical practice means few medical practitioners are familiar with the process and few guidelines are available. Without these, allowing another person to communicate the person's decision carries considerable risk if practitioners are unable to identify undue influence [27]. Australia judicially recognises that people with disabilities enjoy capacity on an equal basis to others under the United Nations Convention on the Rights of Persons with Disabilities [4, 32]. Therefore, it is important for clinicians to avoid

impeding the accessibility of VAD to people with disabilities based on misjudged autonomy.

Identifying mental illness and its effects adds further complexity to the assessment of DMC. Patients accessing VAD commonly have a diagnosis of depression and delirium, and so these become important disorders for practitioners to be aware of, when discussing and engaging with care surrounding VAD [27]. Given the prevalence of depression in terminally ill patients, it is critical that the assessing physician is able to recognise the disorder and refer the patient for psychiatric evaluation [27]. However, the presence of depression and other mental disorders does not always indicate a loss of capacity [23, 27]. A study of 100 elderly people with severe mental illness reported that 65% had DMC for end-of-life decisions [33]. While it is important to consider that DMC is maintained by many people with mental illness, it does merit a thorough assessment. By Victorian law, doctors delivering VAD must be experts in the requesting patient's disease [4]. However, experience in that condition does not equate to acumen in capacity determination [23, 27]. Numerous studies have shown that assessing DMC challenges clinicians, with only 15-30% fully confident in their ability to assess DMC [32-34] Additionally, further difficulty is reported in assessing patients with psychiatric disorders [35].

Those with disability or mental illness form two of the four groups recognised by the Voluntary Assisted Dying Ministerial Advisory Panel as being potentially vulnerable (the others being children and the elderly) [29]. Therefore, it is paramount that safeguards protect these groups in a way that does not impede access and limit autonomy. Accordingly, medical professionals should abandon the view that disability and mental illness are invariably linked to incapacity in order to facilitate a patient-centred approach to VAD.

Cognitive Impairment, 'Enduring' Consent, & Prognostication

VAD legislation stipulates that a patient must maintain DMC from first request to administration to ensure voluntariness underlies the entire process [3]. VAD laws also recognise that DMC fluctuates overtime and may require reassessment on a case-by-case basis [4]. The main determinant of capacity is cognition, and this raises concern for the eligibility of those suffering from conditions causing cognitive impairment [25]. This is especially true for neurodegenerative disorders, where the VAD legislature is called upon to essentially exclude anyone suffering from severe mental disorders [3].

The issue is compounded by the expressive intent of limiting VAD to people prognosed to die within weeks or months of life [3]. Hence, a tension arises between the time frame required for VAD eligibility and the life expectancy of those requesting VAD. With regard to neurodegenerative disorders, even the 12-month timeframe implies a severe stage of disease. In the case of dementia, capacity may be lost as early as mild dementia, and incapacity manifests in 60-75% of those with moderate to severe dementia [27, 33]. As has been reported in Western Australia, the severity of these diseases approaching end-of-life alone places

patients at risk of dying prior to the administration of a VAD substance [35]. Anticipating a loss of capacity may also drive people to access VAD earlier and/ or expedite the process, in fear of losing VAD as an option [36]. A WA clinic also found that people undergoing VAD required additional psychological support to stem this fear of rejection [36].

Mental illness aside, uncertainty in prognostication compounds the difficulty of assessing eligibility and may precipitate a paternalistic approach relying solely on the practitioner's decision. One audit on Victorian VAD patients found that clinicians were unable to prognose 49% of patients [37]. Furthermore, a survey of Australian and New Zealand geriatricians found that up to one third of respondents felt uncomfortable estimating a prognosis [38]. Prognostication is already acknowledged to be 'notoriously difficult' [29] and beyond its subjective challenge, studies have demonstrated the inaccuracies of physicians in estimating death [38]. Concern is also drawn to this safeguard by the fact that a significant percentage of people predicted to die within six months survive for another two to three years [29]. Therefore, this safeguard does not sufficiently align with the VAD policy goal of respecting life as it may allow access to VAD to people who have more than six months of life remaining [29].

With an ageing population likely to make these challenges more profound, it is important that these are addressed through effective end-of-life discussions and advance care planning [39]. An advance care directive (ACD), currently prohibited for use in relation to VAD, would remedy issues associated with fluctuating DMC [3]. This is in contrast to legislation which allows people to express binding instructions regarding their future medical treatment. However, the safeguard protects against events where an ACD would limit autonomy in people who have changed their mind about continuing VAD but are lacking the capacity to opt out of the process. The risk of this occurring is too great to allow an ACD to satisfy the 'enduring' consent requirement if a person loses capacity early on in the process. Comparatively, the use of an ACD could be considered at a later stage such as after the final request (administration request). It would be important for VAD Boards to review each VAD-related ACD on a case-by-case basis, particularly its use in unique circumstances including where DMC is fluctuating or incapacity is anticipated, provided they have maintained DMC to complete the administration request. This would function similarly to the approval for self-administration weeks or months in advance in Victoria. While there is a requirement for a final DMC assessment at the 'administration request' step for practitioner administration, this stipulation is absent in the case of self-administration. Therefore, when it comes to self-administration, the predominant form accessed in Victoria, there is no safeguard ensuring DMC is maintained throughout the entire process [3].

VAD and Palliative Care

It is important to consider the context of VAD within existing patient care frameworks. As outlined earlier, palliative care is a care pathway for a person with an active, progressive and potentially life-limiting illness, and, as such, patients who are interested in pursuing VAD are often also accessing palliative care.

Palliative care affirms life and regards dying as a normal process and emphasises neither postponing nor hastening death [40]. Palliative care is therefore not usually considered to encompass VAD. Instead, palliative care and VAD are often viewed as coexisting but distinct options in end-of-life care.

The reasons that patients with a life-limiting illness intend to pursue VAD are complex and multifaceted. Understanding these reasons begins with understanding the reasons why patients express a wish to die, or a wish to hasten death. These statements, often called desire to die statements (DTDS), refer to explicit expressions made by patients with life-threatening and advanced illnesses to die, or for medical intervention to end their life [37]. International research consistently reports that the reasons patients express a desire for a hastened death or a desire to die are often complex and multifactorial, but that psychological, existential and social reasons are often more prominent than physical symptoms [41,42]. Whilst palliative care is typically effective at relieving physical symptoms, it may be inadequate to support patients who are experiencing psychological or existential suffering [40]. A multidisciplinary approach is commonly required to support patients with psychological symptoms, and additional resources, including those from outside of the healthcare system, may be required to support patients citing social reasons for their desire to die [43].

Additional Australian research has considered the content of DTDS after the legalisation of VAD in Victoria [37]. Existential distress was more common than distressing physical symptoms, but interventions for managing physical symptoms were more frequent than for managing psychological or existential symptoms [37]. Though VAD was legalised, less than one quarter of the patients involved in this study commenced the VAD assessment process, and less than 10% were approved for a VAD permit. This research is consistent with previous studies demonstrating that a small number of patients who express a wish to die through VAD will actually complete the process [36, 37]. Due to the retrospective nature of this particular study, the reasons associated with completion cannot be determined [37]. However, the authors suggested low awareness about the process and limited availability of eligible medical practitioners given the study took place in the early stages of VAD implementation as possible explanations [37].

In research examining the attitudes of doctors towards their potential role in facilitating VAD, palliative care specialists, alongside geriatricians, remain significantly less willing to participate than doctors in other specialities [44]. Reasons given include the concern regarding the risk to vulnerable people and a lack of confidence in estimating a prognosis and assessing capacity [45]. However, at least under Victoria's VAD laws, geriatricians do not fulfil the specialist requirements of the Act to participate in VAD [44].

Data Transparency

VAD statistics are published in mandatory reports from the VAD Boards in Victoria and WA. Although Victoria has recently reported more demographic data, such as

the recent inclusion of participants' education level, there is a paucity of data to compare the discrepancies between people assessed as eligible, compared with those who died via VAD. From 1 Jan to June 2021 for example, the time taken between the first and final request was 11 days for only 25% of applicants, and 17 days for 50%, with 103 cases withdrawn. Of the withdrawn applications, the majority (90) died before VAD medication could be dispensed, which presents a clear objective goal to improve the processing time. However, 13 people had another reason for withdrawal, which included administrative errors, failing to meet decision making capacity, or transfer to a different facility or medical practitioner. For the purpose of improving the implementation of VAD, amalgamating these unrelated reasons into one category is obstructive. Of some encouragement though, the VAD Board has reported that future reports will include 'the applicant no longer has decision making capacity in relation to voluntary assisted dying.' In the latest report, the VAD Board also announced the introduction of a research strategy that would give researchers access to the VAD database [19]. This is a positive step towards unpacking the challenges that both medical practitioners and patients face, however it lacks transparency and precludes medical practitioners, facilities and other researchers from analysing the data.

The Health Practitioner Perspective to VAD

VAD has been available to Australians in various jurisdictions since 2019, and there is a growing evidence base of health professionals' attitudes towards VAD and experiences of being involved in various aspects of VAD.

Research with Victorian doctors likely to receive a request for VAD (including, but not limited to, those in geriatric medicine, general practice, oncology and palliative care) indicated that doctors perceive VAD as a fundamental challenge to traditional medical practice [45]. This was, at least partially, due to the lack of support, and outward opposition, from the medical profession and training bodies like the Australian Medical Association, for the provision of VAD [45,46].

The lack of resources to adequately provide VAD is a barrier to the provision of these services for Victorian doctors. Sixty hours of work is reportedly required from the period of coordinating a patient's VAD request through to their death, and doctors indicate the necessary institutional support and peer networks are often lacking in this process [45]. As an example, Dr Angel Cooney says that he is involved in an average of ten hours worth of work coordinating a person through the VAD process if it is a simple case [36]. However, the Medicare Benefits Schedule excludes many services relating to VAD so only the face-to-face consultation is reimbursed, leaving travel and administrative work unpaid [36]. Doctors are able to privately bill people for these services but Dr Cooney said most see this as unethical [36]. Dr Cooney explained how a number of his colleagues have stopped providing VAD due to difficulty managing the time demanded by VAD cases and time for work that earns them money to support their families [36]. For other doctors, being one of few participating VAD providers resulted in a workload that limited their ability to care for their regular patients. Within organisations or

networks that were not supportive of VAD, doctors have also raised concerns over the reputational impact that may come with being a recognised VAD provider [45].

Furthermore, qualitative research suggests that the mandatory training required by doctors interested in providing VAD may be the largest deterrent to participation. This training takes between six and eight hours and is followed by a compulsory exam. Concerns have been raised over the training's lack of practical clinical guidance, alongside the fact that it is unremunerated and a significant time commitment for already overburdened and overworked doctors [45].

Research into the general attitudes of Australian health practitioners providing VAD care show that willingness to provide such services was variable, with a wide ranging extent of support [38]. Even amongst specialties with low reported support for VAD legislation, like geriatricians, research suggests that over half of these specialists would be willing to refer patients seeking VAD to an appropriate provider [38]. A far smaller number, closer to 10% of participants would actually provide VAD to a patient [38]. Further qualitative and quantitative research with doctors from a variety of specialities suggests a similar pattern whereby the majority of doctors support VAD, but when more commitment is required of doctors, this support decreases. This includes greater time commitment, clinical complexity and emotional involvement [38,45].

For most states, the debate of whether VAD should be implemented is resolved. Moving forward, it is clear that future research should focus on participating doctors, such as the qualitative study by Sellars, White, Yates and Willmott [21]. In a number of semi-structured interviews the researchers reported multiple challenges that medical practitioners face in implementing VAD. Multiple themes were identified, which included the culture of VAD among colleagues, frustration over the safeguards, uncertainty in estimating life expectancy, complexities in assessing decision making capacity (particularly when deterioration resulted in loss of speech or delirium), legal uncertainty in using telehealth, the emotional burden of patients dying before the process could be completed, handling the fear and distress of family members, confronting the emotional burden of practitioner-administration compared to self-administration, frustration and anger over the logistical and technical requirements of the online portal, ethical and moral dilemmas regarding billing patients versus 'pro bono', and lack of psychological support [47]. Unfortunately, VAD is often excluded from end-of-life research grants. As the number of participating practitioners is sparse, particularly in regional areas, further research may redress the barriers that are preventing more doctors from implementing VAD in their practice, which will support unimpeded access for eligible people, and improve implementation of VAD [47].

Accessibility Issues

A known challenge of the policy-making process is balancing the tension between policy goals, for example, providing access to VAD while providing safeguards that protect vulnerable individuals and the wider community. The result was a complex

system of safeguards out of which several issues have arisen in translating the legislation into clinical practice.

Availability of Willing and Eligible Medical Practitioners

Support for VAD amongst medical practitioners who are most likely to receive a VAD request is low [7]. A major challenge in accessing VAD faced by eligible patients is finding a qualified medical practitioner willing to act as either the coordinating or consulting practitioner [36]. In response to poor uptake of VAD training amongst medical practitioners in Victoria, the state established the Statewide Care Navigator Service (SCNS) to support people in finding an eligible practitioner. The success of the SCNS led WA to incorporate the service from time of enactment [36].

These challenges can be further exacerbated in rural and regional areas. For example, in Victoria, there are only 11 eligible oncologists despite 78% of VAD users having a cancer diagnosis [19, 48]. Correspondingly, 15% of VAD requests for people with neurodegenerative disease would not have access to an eligible neurologist in their area as there are zero participating neurologists in rural areas and thus would have to go through metropolitan services due to the lack of an eligible neurologist [19, 48]. As such, significant disparities between the medical condition of the person requesting and medical practitioners with the appropriate expertise to facilitate VAD may delay the process. However, the SCNS (WA) managed Voluntary Assisted Dying Regional Access Support Scheme (RASS) seeks to address that challenge, and provides financial support for people to travel to eligible medical practitioners. If unable to travel, the RASS can support a medical practitioner to travel to the patient [49].

Accessibility under the Victorian Act is also limited by who can be the 'administering practitioner,' which is the professional who delivers the VAD substance in the case of practitioner administration. In WA and other states, nurse practitioners are allowed to assume this role. The Queensland Act also provides for registered nurses "to act as an administering practitioner in areas with fewer medical practitioners," ensuring access to VAD is fairly accessible [50].

Telehealth

Telehealth consultations provide access to patients who are geographically isolated, and is in keeping with the transition of remote consultations due to the COVID-19 pandemic [51]. However a significant and continuous challenge for medical practitioners is the fear of contravening sections 474.29A and 474.29B of the *Commonwealth Criminal Code Act 1995* (Cth) ('*Criminal Code*') written in 2005, that prohibits the use of a 'carriage service' (such as phone or Zoom) to 'incite or counsel another person to commit or attempt to commit suicide' [52]. Despite the VAD legislation specifically rejecting 'suicide' as a term, feedback from medical practitioners suggests that interpretation of the *Criminal Code* provisions are greatly varied, resulting in unstandardised practice. For example, some practitioners have refused to offer VAD services via telehealth under the belief that it is strictly banned [19]. Whereas other practitioners denied that the provisions



apply to VAD, or believed that telehealth was warranted under the current logistical challenges of the pandemic [21]. Understandably, the confusion is compounded by a guidance document from the Victorian Department of Health, which states that all discussions and consultations must be 'face-to-face' due to the *Criminal Code* [53]. Although this document is not legally binding, it is clear that definitive legal clarity is required, especially as Victoria's VAD Act is silent on the use of telehealth. In WA however, s158 of the VAD Act permits the use of telehealth throughout the entire process where face-to-face is not practicable. Despite this, hesitancy is noted in subsection 4 which precludes telehealth to the extent that it is contrary or inconsistent with Commonwealth law [24]. Until this issue is addressed, many eligible VAD patients from regional or remote areas are inherently disadvantaged, particularly as care navigators may also feel conflicted by the *Criminal Code* [7]. The requirements for in person consultations impose increasing challenges, due to geographical and community limitations. In the January to June 2021 report in Victoria for example, one medical practitioner tells of the onerous burden a dying patient had to endure by travelling 5-6 hours for a consultation, which the practitioner described as unfair and undignified [53].

Informed Consent

Informed consent and autonomy (or person-centred care) operate synonymously. The Good medical practice: a code of conduct for doctors in Australia (*Medical Code*) expresses respect for autonomy in advising medical practitioners to encourage and support patients in being well informed about their health, and respecting patients' rights to make their own decisions [54]. The Australian Commission on Safety and Quality in Health Care identifies informed consent as integral to upholding the right to information in accordance with the Australian Charter of Healthcare Rights, which is defined as a voluntary decision that is made following accurate and relevant information about the healthcare intervention and alternative options available with adequate knowledge and understanding of the benefits and material risks [55]. Material risk comes from the case of *Rogers v Whitaker*, in which medical practitioners must disclose any risks that the patient would be likely to attach significance to [56]. Elevating the *patient* as the source of determining the extent of information that should be disclosed, rather than the medical practitioner, supports person-centred care as the cornerstone of valid consent [57]. The requirement for consent to be informed under the *Medical Code* in Australia is enforceable by the Australian Health Practitioner Regulation Agency [58].

VAD is undoubtedly a 'healthcare intervention or alternative option' and subject to disclosure during an end of life conversation for people in WA and Victoria. However, the legal obligation to 'inform' the patient of the requisite VAD information under the WA and Vic Acts only applies *after* the person has made a first request and assessed as eligible. In Western Australia there is an exception; medical practitioners may initiate a discussion around VAD with a patient if, at the same time, they also inform the patient about treatment and palliative care options [24]. In Victoria however, medical practitioners are prohibited from raising VAD as an option and can *only* discuss VAD at the patient's request [4]. Victoria's

prohibition causes several issues. Firstly, it may be difficult to judge whether or not a patient has adequately raised the issue of VAD to a level which justifies the practitioner continuing the discussion [59]. For example, medical practitioners may understandably discuss VAD if the patient expresses a wish to end their life. However, guidance by the Victorian Department of Health and Human Services states that a patient must specifically and explicitly request VAD [53]. Although the guidance is not legally binding, it creates confusion about what constitutes a 'request'.

Secondly, for patients who are unaware of VAD, the prohibition restricts medical practitioners from upholding their patient's right to be aware of *all* healthcare options and alternatives. This is largely at odds with the ethical and professional requirement that consent be informed, as any end of life decision will fail to meet the definition of informed. In its current state, VAD is uninclusive and discriminatory as it is impossible to assess how many people are aware that it is an option. Although VAD is entering its third year, it is possible that people with limited English, living in rural or remote areas, or who are socially and/or technologically isolated may be completely unaware of VAD, or do not fully understand the process or eligibility criteria. Looking at the data in Victoria, 70% of people who accessed VAD were born in Australia and not of Aboriginal or Torres Strait Islander origin (98%), 95% speak English at home and only 2% required an interpreter [59]. The vast majority (86%) lived in a private residence and 64% lived in metropolitan Victoria [59]. Doctors have also raised concerns with regards to patients from non-English speaking backgrounds or those with low health literacy who may not be aware of VAD legislation and their legal right to pursue this option as a valid end-of life care model [21, 45]. Not only does the prohibition detract from equitable access, for some doctors, the prohibition of discussing VAD with patients also resulted in a sense of professional isolation for doctors providing VAD [45].

Language and Cultural Barriers

Culturally and linguistically diverse (CALD) face additional obstacles in accessing VAD. For people who speak a language other than English, the complexities of VAD can be misunderstood, and this has serious ramifications for patient safety. Language barriers lead to miscommunication, subsequently decreasing the quality of healthcare delivery and impacting patient safety. Whilst professional medical interpreter services may help address these challenges, their use is linked with increased appointment length and costs [60]. Anecdotal evidence from WA further affirms how the VAD process is more complicated for people with limited proficiency in English even with an interpreter, but believes these challenges can be overcome with patient-centred care [36]. Thus, it would be beneficial for VAD legislation to be available in more accessible forms to people of varying proficiencies in English. The Victorian Department of Health website provides this function for VAD related information and should be used as a model for other states [60].

Cultural attitudes and stigma surrounding VAD can reduce accessibility to VAD for medical practitioners and patients fearing to speak about death in such a manner.

A study conducted amongst CALD nurses highlights how VAD conflicts with their cultural and religious beliefs [61]. An example of how cultural beliefs can limit one's access to VAD is evident through a Chinese Australian's experience as they reveal they "haven't heard much about this [VAD] because in the Chinese community talking about death is a taboo." Thus, doctors being prevented from mentioning VAD, can alienate a whole community due to their cultural fears of speaking about death [60].

Barriers Faced by Aboriginal and Torres Strait Islander People

This issue can also be compounded by state legislation preventing doctors from bringing up VAD as an option. Dr Poelina, who has extensive experience in Aboriginal health and wellbeing, sheds light on how this legislation could "interfere with realistic conversations about their life and death" as they should have "free, prior, informed consent [62]." The consideration of cultural beliefs and values is also important to ensure the VAD process is patient-centred. For example, discussions with Aboriginal and Torres Strait Islander Peoples should respect their beliefs about death and wellbeing. It is also important for medical practitioners to recognise that the patients may wish to involve their family and community in discussions. In these cases, finding the balance between understanding the importance of family and the requirements of the Act for the person to make a decision themselves is essential [63]. Receptive to the beliefs of Aboriginal populations, the SWCNS (WA) supports an Aboriginal person to die 'on country' by having the administering practitioner travel to the patient through the RASS [63].

Choice of Self or Practitioner Administration

Victorian VAD laws primarily provide for self-administration, where the patient takes the VAD substance themselves. Practitioner administration is restricted to those assessed to be physically unable to self-administer [29] as this safeguard acts to ensure the process is entirely voluntary [64]. In contrast, the latter is accessible to people in WA and upcoming VAD-legalised states who could self-administer, given they satisfy other criteria [29]. In Victoria, 90% of administration requests have been for self-administration. However, in WA, where greater choice is allowed, only 32% of requests asked for self-administration [36]. With the same trend observed in overseas jurisdictions where practitioner administration is more accessible, practitioner administration is suggested to be people's preferred method of VAD [36]. Therefore, its restriction may impede access to VAD by deterring individuals limited to self-administration. However, it would be pertinent to consider how this could contribute to the emotional toll placed upon participating health practitioners.

Management of VAD Pharmacy

Legislation in all states sets stringent guidelines pertaining to the prescription, handling, administration, storage and disposal of VAD substances [5]. The medications have to be stored and dispensed securely, if unused they must be returned to be destroyed [65]. They must be dispensed in a locked box that can only be accessed by the individual with the labelling of the medication being specified in legislation. The VAD board has to be informed of the dispensing [66].

In WA, the VAD Statewide Pharmacy Service exists to oversee the VAD medication provision. This body liaises with medical and nursing staff and authorised disposers to provide, educate, and coordinate safe administration [67]. However, issues have emerged in having a single provider of the VAD medication, with under-resourcing being cited as a cause for delays in medication delivery and preparation [21]. Further, due to the strict transportation requirements, there may be delays in regional or rural patients receiving these medications following their VAD request [21, 36]. Given the VAD process is extremely time-sensitive, this may cause substantial patient distress and potentially lead to an inability to carry out the intended VAD due to not receiving the drugs before deterioration [36].

During the COVID-19 pandemic in particular, there have been issues in doctors needing to personally meet the pharmacist to provide the prescription as email or fax has not been permitted [21]. This has caused concern for doctors regarding this additional time commitment and practical concerns delaying the VAD provision in both metropolitan and rural areas [21].

Management of Conscientious Objection

VAD legislation recognises and allows for conscientious objection (CO), giving registered health practitioners the right to refuse to support or participate in any aspect of the service [7,68]. However, it varies state by state the extent to which they can remove themselves from the VAD scheme. In Victoria and South Australia, medical practitioners are not obliged to refer the patient to another practitioner, or provide further information [7, 69]. Whilst the Victorian Department of Health and Human Services (DHHS) has implemented guidance on how practitioners can manage their CO, however, these are merely guidelines and do not represent explicit legal obligations [70]. Inequity of care can still occur as some patients may receive support from their doctor such as information, referrals and aid navigating the system, whilst other eligible patients may receive nothing at all. Other states mandate for the practitioner to “immediately inform the person” of their CO and provide the “contact details of the VAD Commission” or a practitioner without CO. Without proper transfer of care, a person’s ability to access VAD may be limited.

There are many reasons for practitioner’s CO and it can be broadly categorised into concern for oneself and one’s profession, concern for patients, and moral beliefs and ideologies. However, it should be noted that CO is not the sole reason for doctors not participating in the VAD scheme, there is still a large gap between practitioners who support VAD but do not want to participate in it due to personal reasons such the emotional toll, stress and anxiety and professional reasons such as fear of staff conflicts and harm to their reputation. The legislation fails to distinguish between conscientious and ‘non-conscientious’ objection, making it challenging for the clinical implementation of VAD to balance respect for ‘conscience’, while also facilitating patient access to VAD [7]. The concept of CO also extends to the level of institutions. Like individual practitioners, there is no obligation for health services to enable any part of the VAD process [7].

Health Care Services and Quality of Care

A lack of legislation regarding the role of health care organisations in facilitating creates delays to accessing VAD for eligible patients, prolonging suffering and becoming an overall psychologically burdensome process. Victoria operates using a three “model of care pathways” for health organisations and they all vary in their response to a patient requesting access to VAD [7, 71].

- Pathway A: a “single service” provides comprehensive access to VAD.
- Pathway B: a “partnership service” provides access to some parts of VAD but needs external assistance, for example, using referral pathways to identify an appropriate specialist.
- Pathway C: an “information and support service” does not provide access to VAD but will provide information and support the person to access VAD from a service that can.

The tiered system for VAD creates a differential where there is significant variability in the quality of care patients experience. Given that equal access requires high quality care across a health system, the care provided by pathway C organisations is not consistent with equal access [69]. Pathway B and C also present issues relating to transfer of care and the delays it may cause in accessing VAD. As highlighted in Cana, “delays in accessing” the service “will often have the effect of prolonging suffering, while transfers to other facilities will be particularly onerous and distressing for both patient and family” [69]. Thus, patients’ access to VAD is significantly hindered by institutions’ refusal to be facilitators for VAD, especially for those with already limited access to health services due to other inequities.

Similar to CO, the legislation needs more than just guidelines as to how organisations respond to VAD, particularly those following Pathway C. Consequences of this have already been demonstrated by a multitude of faith-based services electing not to provide information or facilitate access to VAD. For example, Catholic Health Australia, the largest non-government conglomerate of health, community, and aged care services in the country, declared it “will neither provide nor facilitate” VAD [7]. Regardless of the model of care pathway adopted, all health services are advised to educate their staff about VAD and produce policy guidelines that support health practitioners to provide information to patients who request VAD. Despite the encouragement of the DHHS, organisations like Catholic Health Australia have no obligation to assist patients or refer them to a service that will, as in line with the CO in VAD policy [7]. While there are reasons to protect organisations this way, exercising this right is not compatible with equal access for patients [69].

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