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POLICY REPORT

Facilitating regional and remote access to voluntary assisted dying in Western Australia: targeted initiatives during the law-making and implementation stages of reform

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ETHICS APPROVAL

This policy report only analyses publicly available information and does not require ethical approval

ABSTRACT:

Australians living in regional and remote communities face several barriers when accessing high quality health care. Voluntary assisted dying (VAD), a new and sensitive end-of-life option, presents a new challenge for residents living in these communities. Western Australia (WA) is the second Australian state to implement VAD laws and, to date, is the jurisdiction with the greatest need to address access inequities in regional and remote communities due to its vast area. This article identifies and explores initiatives introduced by the WA Government to address regional and remote access inequities in each of the two stages of the reform process: the stage of the reform process leading up to passing the law ('law-making stage'), and the stage of the reform process after the law was passed and prior to it commencing operation ('implementation stage').

The analysis reveals that several initiatives were implemented during each of the law-making and implementation stages of reform. Initiatives introduced in the law-making stage through inclusion in the legislation itself included dedicated guiding

principles promoting equality of access for regional and remote residents, broadened qualification requirements for medical practitioners who can participate in VAD, allowing nurse practitioner administration, and mandating that statistics relating to regional and remote access are recorded and reported. Other initiatives dedicated to facilitating regional and remote access were not specifically provided for by legislation but were introduced during the implementation stage of the reform process. These include the establishment of a Statewide Care Navigator Service that administers a Regional Access Support Scheme and ensuring that the Statewide Pharmacy Service is accessible to regional and remote residents. Other initiatives intended to facilitate regional and remote access were provided for in legislation but given further content during the implementation stage. These include an access standard (contents determined by the CEO during implementation) and telehealth (supporting guidance around lawful use issued by the WA Government during implementation).

This policy report reveals that WA took a considered and targeted focus to address regional and remote access in both the law-making and implementation stages of reform. Given VAD in WA is still in the early stages of its operation, it is too soon to determine how effective these initiatives have been in promoting regional and remote access to VAD in WA. Careful evaluation of these initiatives will be crucial to monitor their effectiveness and to assess whether additional measures are needed. Reflecting on the WA experience will also be valuable for other states as they legalise VAD and develop (and adapt) their own access initiatives.

Keywords:

access, end of life, implementation, initiatives, law, reform, regional, voluntary assisted dying, Western Australia.

FULL ARTICLE:

Context

Australia is a vast country, with approximately 28% of its population living in regional and remote areas[1]. Access to high quality health care is a well-documented challenge for this population when compared to metropolitan counterparts[2]. This population typically has higher levels of disease and injury, lives shorter lives, and experiences more challenges in accessing health services, including end-of-life and palliative care[3]. While regional and remote access to health services is an issue in all Australian jurisdictions, these issues are particularly acute in Western Australia (WA) due to its vast area and population distribution, which comprises many communities with limited access to medical practitioners[4].This policy report will focus on regional and remote access in WA, in the context of voluntary assisted dying (VAD).

VAD is a relatively new end-of-life choice that is available to terminally ill competent adults who can satisfy narrow eligibility criteria. The existence of regimes for lawful assisted dying have expanded significantly around the world in the past 20 years[5].In Australia, at the time of writing, VAD had been legalised in six states (Victoria, WA, Tasmania, South Australia, Queensland and New South Wales) and has commenced operation in Victoria and WA. While there is some variation across states, the legislative models are broadly similar. The practice is highly regulated, and access is only possible with the approval of at least two medical practitioners who have undertaken the legislatively mandated training and possess the necessary level of qualifications and experience (and, in Victoria and South Australia, one of the medical practitioners must have expertise in the patient's disease, illness or condition). The VAD substance is dispensed by a pharmacy, and self-administration (by the person) and practitioner administration (by eligible health practitioners) are permitted.

Victoria's VAD laws, the first VAD laws in Australia, commenced operation in June 2019. One of the practical challenges in Victoria is finding an eligible medical practitioner willing to assist in the VAD process[6,7]. This challenge is particularly acute for those in regional and remote communities[6,8,9]. In Victoria, approximately 35% of practitioners are from regional and remote areas, and only a small proportion of them are specialists[10]. The lack of qualified medical practitioners has often meant terminally ill patients have been forced to travel to metropolitan Melbourne to be assessed. For patients who are too gravely ill to travel, this can mean they are unable to access VAD[6].

Under all VAD legislative models, health practitioners can conscientiously object to being involved. The implications of conscientious objection may be disproportionately great for individuals seeking VAD in regional and remote communities due to the already smaller cohort of eligible medical practitioners[9,11,12]. These communities tend to be disproportionally serviced by internationally trained practitioners[13], who have been found to more likely claim a conscientious objection to 'contentious' medical practices such as abortion[14]. Similarly, reputational and community stigma have been found to deter health practitioners from participating in VAD, which is particularly acute in the regional and remote context given practitioners typically live in the same community in which they practise[6,9,15].

A further barrier for regional and remote access to VAD is the restriction on the ability of health professionals and patients to communicate through telehealth. This restriction potentially applies in the VAD context because of Commonwealth criminal law, which makes it an offence in some circumstances to discuss 'suicide' via a 'carriage service' (such as telehealth). While this law was enacted before state VAD laws were passed, and it targeted different activities, it has potentially criminalises certain aspects of the VAD process that are permitted under state VAD laws and causes significant access issues for regional and remote residents [7,10,16-20].

Equity of access to VAD for individuals living in regional and remote communities will be a challenge for any Australian jurisdiction legalising VAD, and states have taken a variety of approaches to mitigate this inequity. However, recognising such challenges would be pronounced in the WA context – due to the state's geography and population distribution – the WA Government implemented a range of initiatives intended to facilitate access for all potentially eligible individuals to VAD, regardless of where they reside. This policy report explores initiatives used to facilitate regional and remote access in WA, reflecting on the lessons learned and the implications of such initiatives for future implementation of VAD in other Australian jurisdictions and internationally.

Regional and remote access initiatives

The focus of this policy report is on regional and remote access initiatives that have been identified through four sources: VAD legislation or policy, parliamentary debates, the Ministerial Expert Panel (MEP) report (which advised the WA Government on designing the VAD system)[4], and academic literature. These initiatives, identified in Table 1, and described more fully in the commentary that follows, occurred at two different stages of the reform process. The first is the law-making stage (up to 19 December 2019, when the law was passed by Parliament) and the second is the implementation stage (from 19 December 2019 to when the law started in force on 1 July 2021).

Because the WA law began operation in July 2021, the design and implementation phases could draw on early insights from Victoria. However, as was repeatedly noted in the MEP's report, the vast differences between Victoria and WA, particularly in relation to WA's geography, population distribution and cultural diversity, demanded further measures to support the needs of regional and remote communities[4].

Table 1: Overview of initiatives[21-25†]

Initiative	Nature of initiative	Relevant stage
Guiding principles in *Voluntary Assisted Dying Act 2019* (WA)	In a wider list of the Act's guiding principles, there are two principles that promote equality of access for regional and remote residents: (1) A person is entitled to genuine choices about the person's care, treatment and end of life, irrespective of where the person lives in Western Australia (WA) and having regard to that person's culture and language [section 4(1)(h)]. (2) A person who is a regional resident (defined in section 5 as any person who ordinarily resides in an area of WA that is outside a metropolitan area) is entitled to the same level of access to VAD as a person who lives in a metropolitan region [section 4(1)(i)].	Law-making
Qualifications of medical practitioners assessing for eligibility	A medical practitioner must meet the requirements set out by the CEO [ref. 21] to participate in the VAD process and either: • hold a specialist registration and have practised for 1 year as a holder of the specialist registration; or • hold a general registration and have practised for 10 years; or • be an overseas-trained specialist who holds limited registration or provisional registration [section 17].	Law-making
Nurse practitioner administration	Administration of the VAD substance can be performed by eligible nurse practitioners in addition to medical practitioners [section 54].	Law-making
Obligations on conscientious objectors	Health practitioners who refuse a patient's first request must provide the patient with prescribed information [section 20(5)]. Practitioners must disclose their conscientious objection to the patient and referring doctor (where relevant) immediately [sections 20(5), 31(5)].	Law-making
Reporting requirements	The VAD Board (which oversees the VAD system) is required to record and retain statistical information about participation in the request and assessment process, and access to VAD, by regional residents [section 152(1)(c)], which must be included in the annual report [section 155(2)(g)].	Law-making
Access Standard	The CEO must issue an Access Standard that explicitly details how the state intends to facilitate access to VAD for regional residents [section 156]. The Access Standard was issued on 19 November 2020 during the implementation phase [ref. 22].	Law-making and implementation
VAD Statewide Care Navigator Service and the Regional Access Support Service (RASS)	The VAD Statewide Care Navigator Service provides information, advice and support to those involved in VAD including people requesting VAD, their families, carers and health practitioners [ref. 23]. The service is based in Perth, staffed by health professionals and is freely available to all Western Australians. The service also manages the Regional Access Support Scheme (RASS) which provides financial and travel support to assist with VAD access [ref. 23]. The details around how the service would specifically accommodate regional and remote access was provided for in the Access Standard and determined during implementation [ref. 22].	Implementation
Statewide Pharmacy Service	The Statewide Pharmacy Service is a service staffed by qualified pharmacists located in a tertiary hospital that dispenses the VAD substance [ref. 24]. It is available to all Western Australians, no matter where they reside. The details of how the service would facilitate regional access were provided for in the Access Standard and determined during implementation [ref. 22].	Implementation
Telehealth	If it is not practicable for a patient to undertake particular steps required by the VAD Act in person (eg making a first or final request for VAD or administration decision), then the patient may use audiovisual communication. The medical practitioner responding to this may also give the patient advice or information using audiovisual communication. However, communication that would be contrary and inconsistent with the Commonwealth law (the law that prohibits discussions relating to suicide via a carriage service) is not permitted [section 158]. Guidelines issued in the implementation stage provided further guidance about telehealth: '[a]s a general rule, any information that relates specifically to the act of administering a [VAD] substance or provides details or instructions about the act of administering a [VAD] substance must not be discussed via [telehealth]' [ref. 25].	Law-making and implementation

† For the law-making stage, relevant sections of the *Voluntary Assisted Dying Act 2019* (WA) are identified.
VAD, voluntary assisted dying

Guiding principles

During the law-making process, dedicated principles to promote equity of access for regional and remote residents were introduced (Table 1). Principle (1) was recommended by the MEP in response to consultation feedback that there should be dedicated guiding principles related to equality of access[4]. Principle (2) was introduced during the parliamentary debates to acknowledge the government's commitment to providing regional and remote residents equal access to VAD[26].These principles, while not creating specific legal obligations, guide the interpretation of the Act and were relied on to introduce access initiatives for regional and remote residents.

Qualifications of medical practitioners

Due to access concerns about availability of medical practitioners, the MEP recommended that criteria for practitioners to participate in the VAD process be less restrictive than in Victoria[4].The MEP suggested that relevant experience and skills of practitioners were more pertinent than specialist qualifications and noted that many senior doctors working in country hospitals did not have specialist qualifications[4].The MEP recommended that, unlike in Victoria, the legislation should not require participating practitioners to hold a fellowship from a specialist medical college or be a vocationally trained GP[4]. Nor did it recommend that at least one of the practitioners have 5 years' experience post-fellowship or post-registration, or one of the practitioners have relevant expertise and experience in the patient's disease, illness or condition (also Victorian requirements)[4]. WA practitioners must still satisfy the

legislative requirements (Table 1) to participate in VAD.

Nurse practitioner administration

To increase the pool of clinicians available to administer VAD, the MEP recommended nurse practitioners' involvement[4]. By contrast, Victorian law only permits practitioner administration by medical practitioners. The MEP suggested that nurse practitioners' extensive training and scope of practice would make them suitable to participate in VAD, noting that nurse-led teams already provide specialist palliative care in regional and remote WA[4].

Conscientious objection

The MEP considered how conscientious objection could hamper access. While recommending conscientious objection to be permitted, the MEP wanted to ensure that patients were still provided with sufficient information about VAD to ensure access[4]. The access challenges posed by conscientious objection, particularly in regional and remote communities, are widely recognised[9,11,12]. Commentators have raised concerns about the Victorian VAD Act's conscientious objection provision (section 7), and its ability to compound access issues, due to the lack of obligations it imposes on conscientious objectors to refer patients on to willing practitioners or provide information about VAD[8,9]. WA, unlike Victoria, requires conscientious objectors to provide the patient with standardised information, which includes contact details of the VAD Statewide Care Navigator service and information about regional support packages[27].

Statistical information

The Act's requirement to collect and publish statistical information about regional access was an amendment moved during parliamentary debates. It was reasoned that given the commitment to facilitate equal access for regional and metropolitan residents (guiding principle (2) discussed above), parliament should support this initiative to ascertain to what extent this principle is realised in practice[26].

Access Standard

During parliamentary debates, the VAD Bill was amended to introduce an Access Standard, with its content to be determined during implementation. The amendment was moved due to concerns about the access inequities some WA residents face, particularly regional and remote residents[26]. The Access Standard was intended to assist people seeking VAD to understand how they can do so and reflected the Act's principles about equitable access[26]. It was issued in November 2020 and indicated that regional and remote access would be facilitated via the VAD Statewide Care Navigator Service, Regional Access Support Scheme (RASS), VAD Statewide Pharmacy Service and by the state providing clarity about, and monitoring developments in relation to, telehealth[22]. These specific initiatives are discussed further below.

VAD Statewide Care Navigator Service and Regional Access Support Scheme

When considering possible access issues, the MEP recommended establishing a VAD Statewide Care Navigator Service[4]. While the Navigator Service facilitates VAD access statewide, the Access Standard specified that the service would include provision for regional and remote residents to receive information and face-to-face support (if required)[22]. The Access Standard also established the RASS to facilitate access by supporting persons living in regional and remote areas to travel in order to access a practitioner, or support a practitioner to visit the person through payment of travel expenses and remuneration[22]. Further detail about the scheme's travel support is provided in Table 2.

Table 2: Regional Access Support Scheme travel support[25†]

Nature of travel	Support provided	Eligibility
Patient travel to access a practitioner	Travel and accommodation (if required)	• No suitable local practitioner • Telehealth is not appropriate or permissible
Patient travel to access telehealth	Travel and accommodation (if required) to access a telehealth appointment (with VAD Statewide Care Navigator, coordinating or consulting practitioner)	• Travel is more than 70 km one way
Escort travel	Travel and accommodation (if required) of one escort to accompany the patient accessing a practitioner	• No suitable local practitioner • Telehealth is not appropriate or permissible
Practitioner-to-patient travel	Travel	• No suitable local practitioner • Person is unable to travel • Telehealth is not appropriate or permissible
Interpreter travel	Travel	• No local interpreter available • Telehealth or telephone interpretation cannot be effectively undertaken or is inappropriate • Service cannot be accessed under another scheme

† Adapted from Government of Western Australia Guidelines (ref. 25).
VAD, voluntary assisted dying.

VAD Statewide Pharmacy Service

Although a Statewide Pharmacy Service was contemplated during the law-making process, its operation was only determined during implementation. In the parliamentary debates, a hub-and-spoke model was considered optimal, with a central pharmacy service at a tertiary hospital with several regional pharmacy hubs[26], but was ultimately not adopted. The Access Standard provided that the service would actively engage with regional and remote residents to ensure safe, timely and appropriate supply of the VAD substance and ensure regionally based 'Authorised Disposers' could facilitate convenient substance disposal for these residents[22]. The service has also set (and to date met) 5 days as the key performance indicator for supply of the VAD substance, compared to 2 days for metropolitan WA[28].

Telehealth

The MEP's consultation process revealed some support (albeit not universal) for telehealth to enable regional and remote access to VAD[4]. The MEP recognised that telehealth already played a significant role in delivering specialist palliative care in regional and remote communities and acknowledged that electronic information exchange would enable reliable and secure access to VAD statewide[4]. The MEP indicated that access to telehealth would primarily be addressed during implementation, but recommended that there should be no impediment to appropriate use of telehealth in the legislation[4].

The importance of telehealth for regional and remote access, and concerns about the impact of the Commonwealth Criminal Code, were raised in the parliamentary debates[26]. The WA Government indicated that it was in continuing discussions with the Commonwealth and committed to adopting alternative implementation strategies to assist with access if telehealth was not permitted[26].

The Access Standard provided that the state would continue to monitor developments in the Commonwealth Criminal Code and provide clarity around what audiovisual communications could be appropriately utilised[22]. As already discussed, the WA Government issued guidance (via its clinical guidelines) during implementation making it clear that some discussions about VAD should not occur via telehealth[25].

Lessons learned

This policy report has considered an existing challenge (regional and remote access to health care) in the context of a new and sensitive end-of-life option, VAD. This report has focused on WA, the jurisdiction to date with the greatest need to address regional and remote access, and one that has taken specific steps to do so.

Currently, there are limited data available about regional and remote access to VAD in WA, given the official report of WA's VAD operations is yet to be published. However, in June 2022, the WA Minister of Health stated in Parliament that, as of 31 May 2022, there were 68 fully trained medical practitioners eligible to provide VAD, 46 of whom came from Perth (including the Peel region), with the remaining 22 coming from regional and remote areas[29]. The Minister also indicated that 171 individuals have accessed VAD, 21% of whom were located in regional areas[29].The RASS has reportedly been used multiple times to provide access to individuals in regional and remote areas[30]. Despite its acknowledged usefulness, it has been noted that the lack of local practitioners in regional and remote regions means that residents in these areas face greater burdens[30]. Incentives such as remuneration for training have been proposed to help increase the number of providers[31], and there is emerging evidence that the RASS has been used to partly compensate regional practitioners for undertaking the training to assist a particular patient when there are no trained practitioners available in the area[32].

Despite these early indications, it is still unclear how regional and remote access will fare in WA. However, as already noted, there was a considered and targeted focus on regional and remote access in both the law-making and implementation stages of the WA system. Evaluation of the effectiveness of WA's access initiatives and opportunities to improve will be critical. It is significant that regional and remote access is the subject of legislatively mandated data collection and reporting because this facilitates transparent assessment of progress on this issue. Providing health care generally is challenging for regional and remote residents and VAD should not be expected to be any different. However, careful evaluation can assess the effectiveness of the specific measures employed by the WA Government and identify the need for additional measures, if required.

WA is not the only Australian state with regional and remote challenges – indeed all states have them. Significantly, Queensland and Tasmania (two other states that have passed VAD laws that have not yet started) have the most decentralised populations, with the largest proportion of regional residents in the country[33]. Alongside South Australia and New South Wales, these states have made efforts to facilitate regional and remote access in their respective legislation and will likely introduce further initiatives during implementation. There is an opportunity for these implementation exercises to benefit from the WA experience as well as international assisted dying regimes where regional and remote access issues have similarly been identified[12,34]. However, each jurisdiction is different, so any initiative must be adapted to the context in which it will operate.

Importantly, in Australia, some VAD access issues for regional and remote communities are beyond the control of state governments. For instance, VAD systems depend on having sufficient willing and available practitioners. Additionally, restrictions on using telehealth cannot be addressed by state governments and depend on Commonwealth action. Despite the limitations of telehealth, especially in the VAD context, telehealth has traditionally been used to help mitigate access barriers, with a range of different telehealth models being used across regional and remote Australia[35]. Given the burdens this restriction on telehealth creates in the context of VAD, the Commonwealth should amend its Criminal Code[16,17].

Note in proof

Since the acceptance of this article, VAD laws are now also operational in Tasmania, Queensland and South Australia. In November 2022, Western Australia's Voluntary Assisted Dying Board released its first annual report, which details uptake of VAD requests, including among regional patients (https://ww2.health.wa.gov.au/~/media/Corp/Documents/Health-for/Voluntary-assisted-dying/VAD-Board-Annual-Report-2021-22.pdf [https://ww2.health.wa.gov.au/~/media/Corp/Documents/Health-for/Voluntary-assisted-dying/VAD-Board-Annual-Report-2021-22.pdf]). Furthermore, the requirements for remunerating regional practitioners for undertaking VAD training has subsequently been broadened, so its availability is no longer limited to cases where practitioners undertake the training to help a particular patient.

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Declared conflicts of interest

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