LEGISLATIVE ASSEMBLY
FOR THE AUSTRALIAN CAPITAL TERRITORY

SELECT COMMITTEE ON VOLUNTARY ASSISTED DYING BILL
Ms Suzanne Orr MLA (Chair), Ms Leanne Castley (Deputy Chair),
Mr Andrew Braddock MLA, Mr Ed Cocks MLA, Dr Marisa Paterson MLA

Submission Cover Sheet

Inquiry into the Voluntary Assisted Dying Bill 2023

Submission Number: 067

Date Authorised for Publication: 13 December 2023

Submission to the Select Committee on the ACT Voluntary Assisted Dying Bill (the Bill)

Submitted by: Dying With Dignity Western Australia Inc.

Introduction

Dying with Dignity WA (DWDWA) is an incorporated association which has existed for about 45 years. It has more than 600 members and in excess of 7,500 registered supporters. It is an advocacy group which has always sought law reform to provide a lawful choice for assistance in achieving a dignified death, and to avoid unnecessary suffering in that regard.

The *Voluntary Assisted Dying Act 2019 (WA)* (the Act) was passed in December 2019 and commenced operation on 1 July 2021. DWDWA was heavily involved in campaigning for the passage of the Act, and is now participating in the first review of the 'operation and effectiveness' of the Act. We participate in regular consultations with other similar groups in Australia and New Zealand, as well as conferences, and are familiar with VAD legislation in many jurisdictions, including some overseas.

Our submission regarding your Bill will be largely limited to attempting to briefly set our views on the positive aspects of the WA Act and on those provisions which are unsatisfactory; and in commenting on your Bill's proposed eligibility criteria.

As you will be aware, Western Australia's VAD Act was the second in Australia, the first being the Victorian Act. Our Act – like those passed in other states subsequently – essentially adopted the central tenets of the Victorian Act, but, fortunately, omitted some particularly unfortunate constricting features, and so represented a significant improvement. The features in question include a requirement that one of the two doctors assessing the person have specialist expertise in the relevant condition, and a complete prohibition on them raising the issue of VAD with a patient.

On the negative side, in our opinion the WA Act has two major flaws. As well, it could and should be improved by adopting some of the improvements featured in state VAD laws that have been passed since 2019; and, indeed, some of the provisions in the ACT Bill. We will deal with these in turn. (In what follows, we draw substantially on our submission made a few days ago to the panel undertaking the review of the WA Act).

1. **The Bill should allow access to VAD by those who have carefully expressed wishes for such access but who subsequently suffer a loss of capacity (to request and consent to VAD).**

1.1 As argued below, the Bill should be strengthened by following the lead of Quebec in introducing a carefully drafted mechanism to allow access to VAD by means of a prior advance health directive, notwithstanding a subsequent loss of capacity (which ordinarily would preclude a VAD option).

1.2 The first recommendation in the WA Joint Select Committee report was that an expert panel on advance health directives be appointed to consider (inter alia) that people with dementia can "have their health care wishes, end of life planning decisions and advance health directives acknowledged and implemented once they have lost capacity"[1]. This and the other recommendations were well considered, were based on cogent evidence, and were supported by seven of the eight members.

1.3 That panel was appointed but its recommendation on this issue was the only one of 23 not to be implemented. It was that "the State Government consider establishing an Expert Panel to provide advice and recommendations on how to provide people with a neurodegenerative condition access to a choice regarding voluntary assisted dying, in particular through the potential application of advance directives".

1.4 Both the JSC and the MEP just referred to strongly supported the passage of legislation to permit access to VAD by those whose loss of capacity frustrates their clearly expressed wishes.

1.5 The public demand for such access is well established, at least in Western Australia. During the 2019 VAD campaign, it was loudly and clearly raised on many occasions at numerous public meetings organised by individual MPs.

1.6 The MEP established to consider principles for the VAD Bill noted that although the topic was beyond its terms of reference, many representations and submissions to it strongly advocated the same goal. Its report goes on to state that the two main themes to emerge from the consultation were

[1] Recommendation 1, bullet point 4, p 52

the community expectation of being able to access voluntary assisted dying when dementia is present, and the expressed wish for being able to add voluntary assisted dying to an AHD in the event that the person might develop dementia (or in the early stages of having dementia before decision-making capacity is lost). The Panel acknowledged the depth and breadth of such views, and the intensity of feeling that accompanied many of them.[2]

1.7 In an article in the West Australian earlier this year the then WA Premier (Mark McGowan) was quoted as saying – rightly - that it's a "good thing" that there is already a national conversation about dementia, advance health directives and related issues. The current Premier subsequently made similar comments, encouraging efforts to consider amendments to the law in this regard.

1.8 Dementia is the second leading cause of death of all Australians and the leading cause of death for women. Provisional data is showing that dementia will likely soon be the leading cause of death.[3] Many families have been or will be badly affected by this slow and relentless killer.

1.9 Dementia Australia has issued a position statement that says: "As the peak advocacy body for people impacted by dementia, Dementia Australia reflects this diversity of opinion in neither supporting nor rejecting the concept of voluntary assisted dying. What we advocate for is choice and a greater engagement with people impacted by dementia to understand how to best empower them to make decisions about their life and death"[4].

1.10 A very high level of demand from the community for such access has continued following the passage of the Act, and its implementation. It is the issue most frequently raised by DWDWA supporters in meetings, calls and correspondence.

1.11 A loss of capacity may occur prior to the person commencing the request process, or during that process but before the final request is made.

[2] See letter to Roger Cook p.vii of MEP Report; 'two main themes"' and 'Consultation findings 'p. 104; Discussion p.105

[3] Dementia Australia stats updated March 2023

[4] https://www.dementia.org.au/sites/default/files/2023-04/Policy-Position-Statements.pdf

1.12 The second of those cases can and should be dealt with by provisions based on the federal Canadian "waiver of final consent" provisions. These would apply to a person who has been found eligible by coordinating and consulting practitioners, but subsequently loses the requisite capacity. If such a person has executed an AHD in appropriate terms prior to losing capacity, which in effect waives the protection of the further procedural steps normally required (such as the written statement and the administration decision) then VAD will proceed (by way of practitioner administration). This remedy is relatively easily achieved, and should not arouse undue controversy, but on the other hand will avail only a relatively small number of people.

1.13 The first category of case is the larger one. The approach taken in the amendments to the Quebec Act is worthy of close consideration. Although it is extensive and detailed, it carefully sets out a process which will ensure the use of a tailor-made and suitably expressed AHD, and which sensibly addresses the scenario of a person now without capacity who appears no longer to support its implementation. Accompanying this submission is an article by Steve Walker and Dr Richard Lugg entitled "VAD and Dementia – The Quebec Model", which appeared in the Spring 2023 newsletter of DWDWA. This article summarises the relevant features of the Quebec legislation following recent amendments.

1.14 In evaluating the call to allow VAD access to some categories of people who lose capacity, it is important to understand the broader context. When this is done, it becomes apparent that what some might regard as a leap too far is in reality quite a small step.

1.14 As the law stands at present, an AHD can go some way to prevent prolonging the intense psychic and physical pain and distress that often accompanies dementia by specifying clearly what treatment the person wants or refuses and the circumstances in which those decisions are to apply.

1.15 The person could for instance under a valid AHD refuse treatments designed to sustain or prolong life, such as assisted spoon feeding, antibiotics for infections, artificial (or forced) nutrition and hydration etcetera, but request and consent to treatments that would alleviate pain, distress and discomfort with analgesics, oral mouth care, and sedation as appropriate.

1.16 For an AHD to be effective to refuse treatment that will prolong life, but ineffective to request VAD, is a sign of an incoherent policy framework. The

result is that a person may with adequate preparation ensure that he dies a relatively slow death by the withholding of treatment, nutrition or even hydration; but cannot achieve a swifter death by active intervention.

1.17 Of course, amending provisions would need to be carefully drafted to ensure adequate safeguards against duress or coercion, and that the life of someone with dementia could not be ended against that person's will. The new provisions in Quebec's VAD law go a long way to resolving the somewhat intractable and certainly complex issues that arise in relation to dementia, and to balancing safeguards with access.

2. **A "time to death" eligibility criterion which appears in very similar terms in each state VAD Act should *not* be included in the Bill.**

2.1 We heartily congratulate the ACT government in not adopting a criterion of this kind; and we urge that this position be maintained.

2.2 In the VAD laws of every state in Australia, the effect of the "time to death" eligibility criterion is that many people who need it most are denied access to this compassionate law. This sits most uncomfortably with the principles in clause 7(c) and (d) of the Bill regarding autonomy and the minimising of suffering.

2.3 Our submission to the review currently being undertaken by the WA Minister for Health is that s 16(1)(c)(ii) of the WA Act should be repealed. The remaining eligibility criteria in s 16 would be wholly adequate and a more appropriate entry way to VAD, one which has proper regard to the principles of autonomy, compassion, and minimisation of harm and suffering.

2.4 Apart from being of a minimum age, and the satisfaction of residence requirements[5], those criteria are essentially that:

- The condition is advanced, progressive and will cause death
- The condition is causing suffering to the person that cannot be relieved in a manner that the person considers tolerable[6]

[5] Which themselves (ie in the WA Act) should be greatly liberalised or removed, as advocated elsewhere in this submission.

[6] Here we commend the extended definition of suffering which appears in the ACT Bill, which we have submitted should be adopted in Western Australia.

- The person has decision-making capacity
- The person is acting voluntarily and without coercion
- The person's request for access to VAD is enduring[7].

2.5 The six-month and twelve-month dual criteria are arbitrary and unsupported by research or reason. They have their genesis primarily in the arbitrary adoption of a six-month time frame in the Oregon MAiD Act, which in turn was an expedient borrowing of the time frame in use for provision of palliative care in the United States.

2.6 The use of such eligibility criteria also runs counter to the clear recommendations of the WA Joint Select Committee in its report entitled *My Life, My Choice*. In her Foreword, the Chair stated:

> "In the course of the inquiry, the Committee found that a predicted timeframe until death as an eligibility criteria (sic) can result in some individuals being unfairly excluded, and may not be clinically justified. People with progressive chronic or neurodegenerative disease may experience intractable suffering for months or years before they die. The committee has chosen not to ignore the suffering of these individuals.
>
> **The committee has recommended that those who are eligible for voluntary assisted dying must be experiencing grievous and irremediable suffering related to an advanced and progressive terminal, chronic or neurodegenerative condition that cannot be alleviated in a manner acceptable to that person, where death is a reasonably foreseeable outcome of the condition."** (emphasis in original).

2.7 We strongly endorse those views, which were well founded on the extensive submissions and personal stories received by the committee.

2.8 It should also be noted that Queensland has not followed the lead of the other states in this regard, but instead has decided that a simple 12-month criterion is sufficient.

2.9 However – and this is a major point we wish to make - we do *not* support the Bill's attempt to define when a condition is *advanced* (*the individual's functioning and quality of life decline, and any treatments that are available and acceptable*

[7] The satisfaction of the third-last and last of the criteria listed on our suggested model would be mandatory other than in cases where there the person has signed and had approved and registered a specially tailored AHD (pursuant to provisions based on the Quebec amendments).

to the individual lose any beneficial impact, and *the individual is in the last stages of their life*; and *progressive* (*the condition is deteriorating and will continue to deteriorate).*

2.10 The relevant terms should remain undefined, as they are in the WA VAD Act. The ACT proposed definitions are unduly rigid and arbitrary, and go well beyond the words' usual range of meaning. They would likely exclude some conditions which due to their clinical expression may not meet one or other definition, and yet which should qualify when general understandings of the key terms *advanced* and *progressive* are applied.

2.11 To elaborate: we have no problem with para (a) (*the individual's functioning and quality of life have declined*); our problems are with (b) and (c).

2.12 The first of those - *any treatments that are available and acceptable to the individual lose any beneficial impact* - at first glance seems to have some attraction, as of course it conjures up the example of the cancer patient who has exhausted the treatments acceptable to them.

2.13 However, a deep fault lurks within, one which may well render this no doubt well-intentioned drafting reform a giant step backwards in the evolution of Australian VAD legislation.

2.14 A member of DWDWA has applied this test to the situation of a person she knew who was suffering from Parkinson's and some other conditions too. His symptoms had significantly worsened after a number of years, affecting for example his mobility and speech. He had seen his father die a prolonged and horrible death from that same condition. Over many months he encountered major difficulties in obtaining a positive VAD assessment. A neurologist opined that he would likely live for several more years - an outcome he greatly feared. He was continuing to accept and take medications because they resulted in his daily life being less horrible than otherwise it would have been.

2.15 Under the regime of the ACT Bill, if it became law, presumably it would be open to someone in this man's state to decide that the medications were no longer acceptable to him. In that way, the obstacle posed by this definition would be overcome - but at a desperate cost personally, as during the assessment process (which might be a lengthy one, as it had been for this person) the suffering might be immense. In our submission, this paragraph of the definition should be discarded altogether.

2.16 Para (c) - *the individual is in the last stages of their life* - also seems to introduce a disturbingly plastic term that would be extraordinarily difficult to construe. It is a dangerous piece of drafting, as the way in which it might be applied is very difficult to predict (as argued below).

2.17 In our opinion, the defined meaning of "advanced" differs quite significantly from its ordinary range of meaning. The same term is used in the WA Act, where it is not defined. (Tangentially, I note that in the principles stated in the Bill, there is reference to "approaching the end of their life" and an almost identical phrase appears in the corresponding place in the WA Act, and in neither case is there an attempt at definition). In thinking about the ordinary meanings of "advanced", one thinks of something in the order of "more than half-way, towards the end". The Collins online dictionary definition relevantly includes "something that is at an advanced stage or level, is at a late stage of development".

2.18 Our submission is that phrase introduced in the definition - "the last stages of (their) life" - bears a much different meaning, and would lead to a much narrower range of likely applications. The reference is the "last stages", not to the "later stages". Nor is it a reference to stages of the condition(s) or of their clinical manifestations. The essence of the phrase as employed seems to go in the direction of days and weeks, and it does not appear that it would embrace easily a case where the person is assessed as having as long as 6 months to live.

2.19 A contrary argument might be that some of the cohort of people diagnosed with dementia, where the condition had moved beyond the initial stages but capacity was still present, might be assessed as being in the last stages of what in many such instances would by then have been a long life. However, we feel no confidence about that outcome.

2.20 On balance we consider that this definition risks being quite a retrograde drafting step, which may lead to a far more stringent scope of eligibility than that adopted in any Australian state.

3. **Residence requirements**

3.1 The residence requirements stated in clause 11 of the Bill, taken with the power to grant an exemption as provided by cl 151, appear to be reasonable and sensible. Certainly, they are an advance on the residency requirement in the WA Act.

3.2 However, we suggest that the Bill might go further, by omitting altogether any reference to residence in the ACT. Now that every state has passed its own VAD legislation, the only real possibility for so-called death tourism (an ill-named concept) would be for people from the Northern Territory to come to the ACT for relief, and that possibility borders on the fanciful; and in any event the chances are very high that the NT will have its own VAD Act next year.

3.3 The ACT should seize the opportunity to become the first Australian jurisdiction to be open to all persons living in the Commonwealth. It is very likely that in the end all other Australian jurisdictions (and perhaps New Zealand too) will follow suit.

4. Extended definition of suffering intolerably

4.1 We congratulate the ACT on adopting the approach to this definition which is expressed in clause 11 (3). Western Australia is not the only state lacking the clarity achieved by this definition. It serves to ensure that the meaning of this phrase is as expansive as compassion and humanity require.

5. Administration decisions

5.1 We support the terms of clause 42, which we prefer to the corresponding sections in the WA Act.

5.2 In particular, it is clearer, and preferable, to provide that the decision *may* be made in consultation with, and on the advice of, the coordinating practitioner. It is entirely appropriate that this decision be unconstrained by any obligation to consult with another person. The person may well choose to consult with the coordinating practitioner, and generally it may be sensible to do so; but this must be an entirely personal choice for the person involved.

5.3 The Bill appears to permit a rapid and relatively informal process by which the person may change the decision at any time. This flexibility is an improvement on the WA Act. It is sensible to allow for the (probably quite unusual) circumstance where a person has opted for self-administration, but the coordinating practitioner is present when the process begins, and some difficulty ensues while the person remains conscious. The person could then change his or her choice to practitioner administration.

5.4 Perhaps, in addition, the Bill might further make allowance for the possibility that a difficulty in effective self-administration arises *after* the person has lost consciousness. If the coordinating practitioner is present, he or she might be empowered to take whatever steps are clinically necessary to achieve the rapid and peaceful death originally anticipated.

Stephen Walker
President
Dying With Dignity Western Australia Inc.

11 December 2023

Dying with Dignity
WESTERN AUSTRALIA

Volume 43 | Issue 2

NEWS | Spring 2023

President's Report

Welcome to our 2023 spring newsletter. Once again, the main items of business both in the newsletter and at our Annual General Meeting on October 18 are the much-awaited review of the Voluntary Assisted Dying Act, and the associated strong wish of members and supporters to debate and encourage changes to the Act – particularly to relax the rigid eligibility criteria, and to accommodate those suffering from dementia or similar conditions.

In the lead article I have described some of the delays, disappointments and frustrations we are continuing to encounter with the review. Despite these, we still nourish the hope that in the end it will be a true review of the Act's operation and effectiveness, which is what the Act itself requires. For unknown reasons, and to our frustration, as at the time of writing (early September) the terms of reference still have not been released. We remain determined to put to the reviewers the issues which have arisen since July 2021 – and our suggested solutions. We must then hope that the Minister and the parliament will bring open minds to considering the recommendations put forward by, and to, the reviewers.

A particularly vexing issue is the one surrounding dementia. In recent months we have spent much time considering how our Act could address the glaring omission of this ever growing segment of our community from access to VAD. This has included extended discussions with our friends at DWD Victoria, and consideration of ideas from New Zealand, including a possible draft advance health directive for use in this context. It has also involved a close examination of amendments passed in Quebec in recent months to that province's medical assistance in dying (MAiD) law. Those changes achieve exactly what people here are asking for: the ability to sign, while still having decision-making capacity, an approved form of AHD (the terms of which must be endorsed at the time by a doctor as being practicable), so that following a later loss of capacity the person can receive an assisted death when they have reached the stage or condition nominated by them in the AHD. A separate article in this newsletter sketches out some of the details of the Quebec scheme.

In late September a conference on VAD in Australia will be held in Sydney. This has been arranged by our friends at Go Gentle Australia. Both Dr Richard Lugg and I will be attending. The various state DWD groups will also have their own meeting, at which we hope to have a fruitful exchange of views on our present legislative models, important changes to be sought, and 'dementia access' in particular. Another topic will be the continuing failure by the Commonwealth Attorney-General to initiate changes to the federal law that impedes the use of telehealth, and carriage services generally, by medical and nurse practitioners involved in VAD. Dr Nick Carr in Victoria has legal proceedings on foot, but in the meantime I am approaching Kate Chaney (member for Curtin) to ask her to consider preparing a private member's bill.

NOTICE OF ANNUAL GENERAL MEETING OF DWDWA

Date & Time: 2pm 18th October 2023

Location: Citiplace, Concourse Level, Perth Railway Station

Another article in this newsletter considers a court decision in Montana some years ago that held doctors' actions in providing a lethal prescription to a terminally-ill patient to be lawful, even in the absence of an enacted law allowing VAD in that state.

The Minister for Health - who is resisting legislative change - recently suggested that a legal challenge outside the parliamentary process might be successful in extending access to VAD to dementia sufferers in WA. However, we doubt that the Montana decision provides a useful model, since that ruling was predicated on the person having decision-making capacity.

Of course, other matters will also feature in our submissions to the review. Examples that come to mind are the arbitrary and limiting eligibility criteria based on estimates of time to death; and the nonsensical ability of institutions to purportedly exercise a right of conscientious objection on behalf of all their staff, when a moment's reflection makes obvious that such a right can be held and exercised only by individuals. This 'institutional conscientious objection' is a real problem which limits the opportunity to access VAD. It is the subject of another article, this time by Gail Wyatt and Richard Lugg.

Please come to our AGM, and also make your own submissions to the review. We will alert you once the terms of reference are announced. As usual, we ask any member with the time to do so to nominate for election to the committee, or alternatively to let us know whether they can assist with particular tasks. Any help is welcome.

Steve Walker
President, DWDWA

Review? What review?

For a long time now we have been talking about the review of our Voluntary Assisted Dying Act being imminent. In passing the Act in December 2019, the state parliament expressly required that the Minister for Health must review "the operation and effectiveness" of the Act, and prepare a report based on the review, as soon as practicable after the second anniversary of 1 July 2021 (when it began operation). After that, there must be similar further reviews, but only at intervals of no more than five years.

In August 2022 the Minister at our request met with us to discuss the review. We explained that our members and supporters wanted the review to be timely, independent and broad-based, and for the terms of reference to be unlimited in scope. Now, more than a year later (as I write in early September) still no terms of reference have been made available. This delay is very troubling. No explanation for it has been given.

Written indications over the last few months have made it clear that the review will be confined to so-called 'urgent' issues. For instance, the Minister has apparently ruled out any substantive amendments to the Act, including changes to the eligibility criteria. This puts any amendment to the prognosis requirement - that in order to qualify for VAD a person be within 6 months of death, or 12 months for neurodegenerative conditions – beyond the scope of the review. The removal or modification of this impediment to access could alleviate the prolonged and extreme suffering of many who seek to die with dignity: if this is not an urgent issue, what is?

It is the strong view of the committee that any review of the Act's operation and effectiveness must consider other legislative models, both in Australia and overseas, to measure against them how effective our Act has been in meeting its aims and underlying principles. There are some significant variations in the VAD legislation passed by the Australian states. As just one example, Queensland relaxed the '12 months/6 months' rule to a simple and more liberal 12 months for all cases.

Our expressions of concern to both the Minister and the Premier about these issues have yielded no real result, and indeed very little at all by way of response. It has been most disappointing and frustrating, then, to have had to wait for many months with no effective input into the framing of the review, with serious and unexplained delays, and all the while having to conclude from various hints and comments that the review required by law will be nothing more than a bureaucratic exercise in window-dressing.

The most common demand for improvement to our Act is to allow the growing numbers of those suffering from dementia (and other conditions causing cognitive impairment) access to VAD. By the time death has become imminent, most of these people will not have the 'enduring capacity' required to qualify for VAD. Belgium, The Netherlands and Luxembourg, and now Quebec (see separate article in this newsletter) have taken careful steps in this direction. We acknowledge that this issue and especially the working out of appropriate criteria are complex and difficult, but as a community we need to begin the necessary discussions that will sooner or later lead to change.

In this context we were heartened that the former Premier, Mark McGowan, earlier this year, and the present Premier, Roger Cook, more recently, both noted the need for this matter to be considered and discussed. It has been all the more disappointing, then, to learn that the government as a whole seems determined to turn its face against any such discussion, and to rule out even the consideration of submissions advocating for such changes. We await the terms of reference to see whether these somewhat dispiriting predictions are realised.

There is clear evidence that a large proportion of the community wants and expects the government and the Minister to foster, or at the very least permit, such discussions – and to keep an open mind on the matter until the review reports. Democracy requires no less.

We call on members and supporters to contact their local state members of parliament, and the Minister, to demand that a full, open and genuine review is conducted, in particular regarding eligibility. Further, we advocate that regardless of how the delayed terms of reference actually read, your submissions should loudly and clearly state your wishes for changes to the Act. We will be doing the same ourselves.

VAD and Dementia - Lessons from Montana

By Dr Richard Lugg & Steve Walker

In 2008, a retired truck driver, Robert Baxter, lay dying in Montana from lymphocytic leukaemia with diffuse lymphadenopathy. Montana had (and still has) no VAD law, although palliative sedation has sometimes been practised in the management of terminal patients with intractable suffering. This was not acceptable to Robert Baxter, who expressed his attitude in the following terms:

> *I understand that terminal or palliative sedation would involve administering intravenous medication to me for the purpose of rendering me unconscious, and then withholding fluids and nutrition until I die, a process that may take weeks. During this final period of my life I would remain unconscious, unaware of my situation or surroundings, unresponsive from a cognitive or volitional standpoint, and uninvolved in my own death ... My family would be forced to stand a horrible vigil while my unconscious body was maintained in this condition, wasting away from starvation and dehydration, while they waited for me to die. I would want to do whatever I could to avoid subjecting my family to such a painful and pointless ordeal.*
>
> *While the option of terminal sedation might be acceptable to some individuals – and I respect the right of others to choose this course if they wish to – it is abhorrent to me. The notion that terminal sedation should be the only option available to me if my suffering becomes intolerable is an affront to my personal values, beliefs, and integrity.*

Robert Baxter's horror at the prospect of drawn out terminal sedation rings as poignantly down the years as it ever did.

His case eventually found its way on appeal to the Montana Supreme Court, which in 2009 held that there was no existing case or statutory law in Montana that could be reasonably interpreted as reflecting a public policy against the provision of

a lethal prescription to a terminally ill patient with decisional capacity who requests it for the purpose of self-ingestion.

That ruling still stands, permitting VAD by self-administration in Montana, the only US State where it is legal in the absence of an enacted law. This court decision is noteworthy because it is the only one of which we are aware, to legalise a form of VAD on grounds unrelated to human rights charters. On the other hand, courts have held that charters or statutes of human rights provide for or require authorisation of VAD in Colombia (1997), Canada (2016), Luxemburg (2019), Germany (2020), Spain (2021) and Portugal (2022).

Is this significant for the prospects of reform in Western Australia to accommodate patients with terminal dementia? In this state, which has no charter of human rights, the Minister for Health, Amber-Jade Sanderson, has resisted calls for extending the WA VAD legislation. Instead, she has gone on record as saying:

> *The only way that I could see it [VAD in cases of dementia] happening is if it was a Christian Rossiter-style challenge to someone's individual rights to access it. So a common law, potentially, precedent, rather than in statute.*

The Rossiter decision – in the Supreme Court of Western Australia - recognised that a competent person could refuse life-sustaining treatment. It has no application to a person who has lost the capacity to request assistance under our Voluntary Assisted Dying Act but has some similarities to the Baxter case in Montana.

It is important also to consider the question of terminal sedation (also known as palliative sedation). According to the Victorian Department of Health, it is generally recognised as a medical management option for terminal patients in certain circumstances, although its legal status remains undefined. The general view is that it should:

- neither hasten nor postpone death
- be for the relief of intractable physical (rather than existential) suffering
- be confined to use where the patient's prognosis is two weeks or less
- be subject to the informed consent of the

or the family more generally.

Terminal sedation was considered by the WA Joint Select Committee on End of Life Choices, which recommended that WA Health should provide specific guidelines on its use by health professionals for patients at the end of life, and that it should be specifically noted in the medical record. The Government supported this recommendation, noting that further work would be required. However, nothing further has been heard from the Government on this.

Once physical suffering from the cessation of nutrition and hydration has commenced, it would be reasonable to expect a prognosis of no more than two weeks, making that a suitable justification for the introduction of terminal sedation. It should be remembered also that terminal sedation in practice is not always done with consent. Applying the reasoning in the Baxter case, it could be argued that once that point is reached, the doctor's involvement in the death of the patient is essentially the same, whether through terminal sedation or assisted dying.

However, we suggest that while a legal challenge to permit VAD in cases of dementia might superficially appear attractive, there are strong reasons to doubt its prospects of success. Those reasons include the prohibitions in this state's Criminal Code against taking steps to end the life of another. And it is here that our law appears to be crucially different to the statute law of Montana, on which the Baxter decision ultimately turned.

The plaintiffs in that case included several doctors, who were concerned that they might be prosecuted for providing aid in dying. The court therefore analysed their possible culpability for homicide by examining whether the consent of a mentally competent and terminally ill patient to his doctor's aid in dying actions could constitute a statutory defence. A statutory consent defence – available generally, subject to certain exceptions - would be rendered ineffective if permitting the conduct or resulting harm was against public policy. In this way, a finding that the conduct was not against public policy decided the case in favour of Mr Baxter and the other plaintiffs. This line of reasoning would not appear to be available in Western Australia, as a defence of consent would never be open.

We suggest that the only way forward in extending the right to choose VAD to those suffering from dementia and similar conditions is for the parliament to amend the VAD Act. This does involve some complex issues which require careful consideration. The Minister for Health should take the lead - and should do so in the course of the review which is now overdue.

VAD and Dementia - The Quebec Model

By Dr Richard Lugg & Steve Walker

On 7 June 2023, the Parliament of the province of Quebec (in Canada) made changes to its "Act respecting end-of-life care and other legislative provisions" – in an amending Act known generally as Bill 11. It was assented to the same day, although not all of its provisions have yet come into force.

The earlier form of the Act had already permitted medical assistance in dying (MAiD, the equivalent of our Voluntary Assisted Dying) to be provided to a person suffering from a serious and incurable illness and in an advanced state of irreversible decline in capability, and who was experiencing enduring and unbearable suffering that could not be relieved under conditions the person considered tolerable. However, this was limited to a person who had requested MAiD themselves, in a free and informed manner, by the prescribed form, and who also, prior to becoming incapable of doing so, had given consent in writing.

The amendments create an additional gateway to eligibility for MAiD, for people who have lost the cognitive or mental capacity which is ordinarily necessary for eligibility. In some cases, it will be enough if the person has provided the written consent while still having capacity and within 90 days prior to administration. In other cases, a key requirement is the prior execution of a suitable advance request for MAID, but in addition there are several other quite strict safeguards or limitations.

To the best of our knowledge, Quebec is only the fifth jurisdiction to have introduced such provisions, which make it possible for those suffering from dementia or other similar conditions to access voluntary assisted dying. The others are The Netherlands, Belgium, Luxembourg and Colombia. In each case, it appears that the numbers who have been or will be assessed as eligible are very small. The purpose of this article is to summarise the key criteria which are at the centre of the Quebec amendments.

When the existing provisions of the Act are taken into account along with the amendments, the result is that for a person to become eligible for MAiD when capacity has been lost, the following criteria must all be satisfied:

1. The person while still having capacity must have signed and registered an advance request which states reasonably identifiable clinical manifestations which will be the trigger for a MAID examination and possible administration;

2. In order for the advance request to be valid, a medical professional must have considered prior to its execution that its description of those clinical manifestations was acceptable, and have signed off on them;

3. The treating doctor or nurse practitioner (competent professional) must have undertaken a full examination of the person to reach a conclusion as to whether the clinical manifestations stated in the advance request have now occurred (it should be noted here that there are obligations on carers, medical professionals and other third parties at the relevant time to draw to the attention of treating doctors that in their opinion this may be the case);

4. To reach a positive conclusion, those clinical manifestations must be exhibited on a recurring basis;

5. In addition, the person must now be in a medical state of advanced, irreversible decline in capability;

6. Further (and crucially) his or her medical state must give a competent professional cause to believe based on the information at their disposal and according to their clinical judgement that the patient is experiencing enduring and unbearable physical or psychological suffering that cannot be relieved under conditions considered tolerable;

7. The competent professional must obtain the opinion of a second competent professional confirming that these criteria have been met;

8. Any refusal to receive MAID "expressed by the patient must be respected and it is prohibited to disregard it in any manner";

9. Finally, if the person is "exhibiting behavioural symptoms resulting from their medical state, such as resistance to care", the competent professional must, based on the information at their disposal and according to their clinical judgement, rule out the possibility that the person is refusing to receive MAID – and must record in writing the symptoms observed and the conclusions of the assessment.

It is important to realise that these consolidated criteria represent a cascading series of requirements, all of which must be satisfied. Together, they represent a quite daunting and strict set of hurdles to be jumped. Many people will not be able to qualify. This is very far from a carte blanche approach which would wave through all those who have previously signalled an interest in having a voluntary assisted death in some vaguely described circumstances. Nor even will it permit a relative, friend, guardian or alternate decision-maker to decide on behalf of the person.

In short, this is a well-considered, carefully crafted and narrowly limited scheme that should be seen as a conservative effort to meet the very widespread demand in the community for an extension of eligibility to at least some of the large number of sufferers from dementia and similar conditions. In my view, it should be carefully considered for Western Australia.

Some aspects may need special attention. These may include the fact that the tests stated in 8 and 9 above may give rise to some inconsistency or other difficulties. In addition, it might be thought that a better mechanism is for the individual to be empowered themselves to state in their AHD precisely what the administering practitioner's duty is if the by now cognitively impaired person shows apparent resistance to the administration. Perhaps a role for an enduring guardian ought to be considered. On a very practical level, in WA, despite very many years of promises, we still lack a register for AHDs, and this must be created.

Ultimately, the point is that other jurisdictions have grappled with the compelling call from the community for this omission in VAD laws to be dealt with. It is time for our authorities to do the same. To put their collective head in the sand is no solution. Both the joint select committee in its 2018 report and the later Millman ministerial expert panel called for action. Such action is well overdue.

Hospitals, hospices and homes - Their conscientious objections

By Gail Wyatt & Dr Richard Lugg

The Canadian MAID (Medical Assistance in Dying) system was legalized in 2016. In Canada, as in Australia, many hospitals and hospices ('health facilities') and aged care facilities ('homes') want to opt out of VAD altogether for religious or other reasons. Here we explore why Australian hospitals are legally able to do so, while aged care homes are not. But first what is the impact on the community?

As in Australia some health care facilities in Canada refuse to allow or provide MAID (VAD) on-site because of their religious affiliation. Three quarters (73%) of people across Canada believe that publicly-funded health care facilities should be required to provide access to the full range of services, including MAID.

The following Canadian case has chilling similarities to Australian experiences. It illustrates the need to deny any validity to the existence of so-called "institutional rights:"

> *By now you've probably heard the story of Sam O'Neill, a young woman in British Columbia who was required to transfer from her community of care at St. Paul's Hospital, a publicly-funded religious health care facility, to access her assisted death – a gruelling process that required Sam to be medicated for the pain. Sadly, Sam never awoke and was unable to say goodbye to her family and friends. If you have a personal story of a person in your life who faced a barrier in accessing MAID as the result of an institutional religious obstruction, please share your story with us.*
>
> *The law allows clinicians who do not want to be involved in MAID for conscience reasons to opt out. And that's okay – there are clinicians who do want to do this work and are prepared to do it in any health care facility. What's not okay is an institution claiming conscience rights. That's why, after years of stories about forced transfers and their impacts, DWDC is preparing a legal challenge to end this practice across Canada, once and for all. If you, like 73% of people across Canada, believe that publicly funded health care facilities should be required to provide the full range of health care services, including MAID, if they have the proper equipment and staff to do so, then tell your local Member as well as the Minister of Health in your province or territory that institutional religious obstructions must stop.*
>
> **2023 Poll Support for MAID**

Hospitals and Hospices ('Health Facilities')

Now in 2023, DWD Canada is starting a campaign to prevent institutions that accept public funds (including 'healthcare facilities') from exercising any "right" to deny access to MAID (VAD) procedures. This does not deny persons who work in such institutions the ability to exercise their right of conscientious objection to participating in the VAD process. It is based on the simple fact that both ethical codes and the law generally accept that a right to conscientious objection is an individual right that does not inhere in groups whose members are dictated to by its hierarchy.

We know, of course, that this is not the reality in Western Australia. The Catholic Church, for instance, "does not authorise" any of its staff to provide VAD services (effectively a prohibition, though not in so many words). So how can VAD service providers assist people in religiously-affiliated health facilities?

The land is often not public land, and so the health facilities have a general right to exclude trespassers. It is generally accepted that doctors cannot enter to provide medical services unless the health facility has accredited them to do so.

As far as employees are concerned, while our VAD Act protects people against discrimination for the provision of VAD services, it does not protect employees or contractors (who might be dissatisfied with the institution's VAD policies) against failure to renew contracts. And it is widely understood, anyway, that if an employer does not want to renew a contract, it can generally find some sort of ostensible reason for not doing so.

Aged Care Facilities ('Homes')

Lack of information on facilities' end of life policies has meant people going into aged care facilities are not able to easily identify services and facilities that would best suit their needs if VAD became their choice.

Unlike hospitals and hospices, aged care facilities are people's homes and people often nominate their doctor. For this reason, the VAD Acts in some states - unlike in Western Australia – make express provision for rights of residents (and patients in health facilities) to access VAD services, so that such rights are not dependent on the whim of the operator. Notwithstanding Commonwealth legislation to the contrary, this remains a serious omission in our State law. Many people who are likely to want VAD cannot get it - at least not without considerable mental and physical distress.

If you find yourself living in many aged care facilities in this State you may face an uphill battle

over and above dealing with your terminal illness and the challenging VAD process. This is because you are in the charge of a service provider which asserts an 'institutional objection' to VAD and will try to prevent some or all of the processes from taking place on its premises (even if receiving public funds and while professing to be delivering person-centred care).

So this year DWDWA has conducted a survey of aged care facilities' VAD policies across Western Australia. We will publish the findings soon on our website and on social media platforms.

As with the Canadian health care facility experience, this is a compelling issue for our aged care sector. Many Australians are realising the statistical likelihood they will suffer serious ill health towards the end of their lives and want VAD to be a choice they can explore without attempts at obstruction from within their aged care home.

In the survey we encouraged providers to respond by pointing out that the benefits to them include improved relationships, and more trust and transparency in the sector. However, of the 51 facility operators surveyed only 16 (three undecided) have responded to varying degrees in the affirmative. Not surprisingly, the majority of those with clearly supportive policies are the well organised, religiously unaffiliated organisations.

Of concern was the survey finding that many care facilities appear to be disinterested or even unaware they should meet the minimal requirement not to obstruct people's right to VAD. Some openly express no intention of meeting that obligation. Most have simply not responded to enquiries. None makes their position on VAD readily accessible to prospective clients on their websites, which of course effectively prevents such people from gaining this critical information.

Your Feedback Sought

The VAD Act is supposed to protect people against discrimination regarding the provision of VAD services, but in reality this does not provide adequate protection to people in hospitals or hospices, or freedom from obstructive behaviour for people who live in aged care homes. Western Australian regulating authorities do not show signs of acknowledging and acting on non-compliance, even though such behaviour does not align with the WA End-of-Life and Palliative Care Strategy Priorities published by the WA Department of Health. [1.]

DWDWA wants to make the current situation more widely known to intending residents before they commit to a particular provider. If you are able to assist we would welcome information on:

1. Any interaction, positive or negative, you have had with prospective aged care providers over their position on VAD.

2. Your views on whether aged care facilities should have to publish their VAD positions on their websites and in communications with prospective clients.

Responses marked 'VAD Mapping' can be emailed to - **info@dwdwa.org.au**

In a poll conducted on behalf of Dying With Dignity Canada in June 2023, seventy-three per cent of those who identify as Catholic and 63% of Protestants agreed that publicly funded health care facilities should be required to provide the full range of health care services. There is no reason to think that Australian attitudes are significantly different.

We suggest that this topic is an important one for the review of the Western Australian VAD Act, and that it will be worth following developments in Canada closely!

[1.] 1. Care is accessible to everyone, everywhere. 2. Care is person-centred. 3. Care is coordinated. 4. Families and carers are supported. 5. All staff are prepared to care. 6. The community is aware and able to care.

WA End-of-Life and Palliative Care Strategy 2018-2028

Notice of 2023 Annual General Meeting

Date: Wednesday 18 October 2023

Time: 2.00p.m.

Place: Citiplace Community Centre, Upper Concourse, Perth train station, Cnr Wellington and Barrack Streets.

Registrations essential
Please RSVP to info@dwdwa.org.au

DYING WITH DIGNITY WESTERN AUSTRALIA (INC.)

PO Box 7243, Cloisters Square, Perth 6850
Email: memberships@dwdwa.org.au

MEMBERSHIP RENEWAL FORM

Membership year runs from 1st of July to 30th of June of the following year

Standard Rates

- ☐ Single $20
- ☐ Double $30
- ☐ Life Single $200
- ☐ Life Double $300

Donation $_____

Pensioner / Student Rates

- ☐ Single $15
- ☐ Double $25
- ☐ Life Single $150
- ☐ Life Double $250

(Rates unchanged since 1st July 2009)

Payable to DWDWA at the above address or at any Commonwealth branch or online:
Account **DWDWA - BSB no: 066-000, Account no: 17168079.**
To renew through our website please use the "Become a Member" link or payment will be receipted as a donation. Alternatively please complete this form and forward it to us, or bring it with you to the meeting.

Please print clearly

First name _____ Surname _____

Address _____

Postcode _____ Phone _____ Year of birth: _____

Email _____

ARE YOU A FINANCIAL MEMBER?

If the address label on this newsletter has a date ending in 22 (or earlier), **your subscription is no longer current**. If it ends in 23, your renewal is due in July or before. Life members are noted as such and don't need to pay subs, although donations are always welcome.
If paying by bank deposit, particularly over the counter, please ensure your name is included.
For more information or to get an application form for a new member, please contact DWDWA by email to memberships@dwdwa.org.au or see our website www.dwdwa.org.au

BEQUESTS AND DONATIONS

DWDWA is an independent, non-profit, advocacy organisation and totally reliant on membership fees, donations and bequests for our funding. We are always very grateful for donations and bequests which enable us to further our aims. You may remain anonymous and do not need a new Will if you sign a short codicil.

JOURNAL – ISSN 0813-5614

DYING WITH DIGNITY WESTERN AUSTRALIA (Inc.)
ABN 16 953 675 488

Postal address: DWDWA, PO Box 7243, Cloisters Square, Perth, WA 6850, Australia
Email: info@dwdwa.org.au
Internet: www.dwdwa.org.au
Facebook: https://www.facebook.com/dyingwithdignitywa/

EMAILING NEWS TO YOU

If you prefer to receive your newsletter via email (it saves trees), please let us know at memberships@dwdwa.org.au.

DWDWA NEWS
If undelivered please return to:
PO Box 7243, Cloisters Square, PERTH WA 6850

Print Post Approved
PP 607 603 /1117