



Volume 45 | Issue 1

NEWS | Autumn 2025

President's Report

MY NOMINATION AS AN INDEPENDENT IN THE WA ELECTION

It is a fair question. Why did I in February 2025 stand down as President of Dying With Dignity Western Australia and nominate as an independent for the Legislative Council in the state election held on 8 March?

As I write this article the results for the upper house are not yet available. They should be announced in about the second week of April. Before then, there will be no inkling of my chances of gaining the final 37th seat - as no progressive counts of below-the-line voting will be released.

I now return to answer my question. As many readers may have worked out I did so out of my accumulated frustration and deep disappointment at the conduct by the Health Minister Amber-Jade Sanderson of the so-called review of the Voluntary Assisted Dying Act in 2024 – and the Premier's apparent support of that conduct. I should spell out the elements of this story, although in previous newsletters I have related some of them.

The review was required by law, and the Minister's report had to be tabled in parliament by 1 July 2024. Symptomatic of the arrogance surrounding the Minister's arrangements for the review is the fact that the report was tabled four and a half months late (without any apology or explanation). Worse, the entire review was a sham. It was engineered to achieve a pre-ordained outcome

– a conclusion that the parliament should not consider any amendments to the Act. How was this done?

The first step was to ensure that the review was not independent of the Minister. This was in breach of an express undertaking given by her to DWDWA. Of the three reviewers, one worked for her and another was a political ally.

The second was to do everything possible to hobble any prospect that the review might consider any changes to the narrow and restrictive eligibility criteria for voluntary assisted dying. Most of all, the Minister was determined to avoid public pressure or even discussion of (a) the scope of the Act to permit access by people facing a loss of capacity through dementia or other causes and (b) removing or even relaxing the unnecessarily rigid criterion that to qualify a person must be only 6 months from death (12 months for neurodegenerative conditions).

DWDWA made detailed and well-argued written and oral submissions on the need for Western Australia to consider adopting such changes (among others). In doing so, it referred to examples of laws in Queensland, the Australian Capital Territory, Quebec, and Canada as a whole. The ACT has legislated for VAD without a particular time-to-death criterion, while Quebec has provided for advance health directives to avoid the usual need for capacity to continue until death, and Canada allows waivers of the final consent requirement. The Minister avoided

NOTICE OF GENERAL MEETING OF DWDWA

Date & Time: 2pm 21st May 2025

Location: Citiplace, Concourse Level, Perth Railway Station

such debates by the simple device of excluding from the report any mention of these detailed submissions. To call a spade a spade: in my opinion this was a fraud on the parliament and the public.

If the Minister's review report had addressed the considered submissions which argued for amendments, and rejected them, giving reasons, many would have been disappointed. But at least that would have been an honest and open instance of democracy in action. Instead what was foisted upon the parliament and people of Western Australia was a contrived outcome aptly described by a correspondent to The West Australian as an exercise of smoke and mirrors.

In summary, the writers of "Yes Minister" would have been proud of the Minister's formula:

1. Appoint a majority of reviewers who are not independent of the Minister.
2. Write terms of reference that actively discourage submissions seeking amendments.
3. Limit the consultation to specified stakeholders, and if they have the temerity to argue for amendments, ignore them: leaving the parliament, the public and posterity to think that no such submissions had ever been made.
4. In the brief review report express the unsubstantiated conclusion that the Act requires no amendments.

This is what caused me to nominate. It is a stain on our democracy.

I made the decision after first exhausting every means of persuading the government to either have a comprehensive and open review or to make an election commitment to constitute a new parliamentary joint select committee - to dispassionately and honestly assess legislative advances made in other Australian and overseas jurisdictions since the passage of our Act in 2019, and make recommendations on their suitability for our state; in other words, to do the work that should have been done by the Minister.

Having tried for more than a year to speak with the Premier about these matters, finally I was able to meet with him in September 2024. Following that meeting, however, he failed to act on my request for a commitment to a new joint select committee.

Nor did the Labor party give any response to the two surveys sent by DWDWA about this point and about its proposed improvements to the legislation.

By February 2025 it was obvious that the die was cast. I decided to nominate for election as an independent to raise all of these matters in the public arena.

The result is awaited.



Steve Walker
President, DWDWA

Stop Press

Since my report was written, the WA Electoral Commission has announced the results for the Legislative Council. I was not one of the 37 candidates who were elected.

A lot of effort went into the campaign. I would like to warmly thank those who donated or supported me in various ways.

The campaign argued for serious consideration of reform to the VAD Act to permit more people a choice to end suffering at the end of life. Unlike the Victorian government, last year the Western Australian government refused to permit any such consideration. DWDWA will urge the new Health Minister to make a fresh start with a proper review or inquiry aimed at adopting reforms, including the abolition of the time to death criterion and opening up access to those who may lose capacity prior to their death.

Committee changes

In recent months there have been some changes to our committee membership and sharing of responsibilities.

Alan Pugh has found it necessary to retire, in view of family health issues. Alan has been a stalwart in the committee for many years. For a long period he was our Treasurer - a consuming and at times frustrating portfolio. At all times he has been not just stoic and helpful, but also collegial and has leavened proceedings with his laconic humour. Thank you, Alan, for your great contributions.

At the last AGM, Margie Lundy returned to the committee. Her long experience - also as Treasurer - is proving to be most valuable in all of our considerations.

Peter Wilkins also joined the committee at the last AGM. His varied experience within the public service and his perceptive advice quickly showed his worth. Unfortunately for us, Peter and his wife have now relocated to Melbourne (for understandable family reasons). This means that while in the meantime he remains a committee member, and can still contribute while “working remotely”, he is quite unlikely to continue beyond the forthcoming November Annual General Meeting. Dinny Laurence has contributed immensely, including contributions to this newsletter and in updating the website.

One or two other current committee members have had a few health issues. Needless to say, none of us is getting any younger. Intermittently many of us have had time off for travel (a welcome means of recharging the batteries).

From February this year I have been on leave from the position of President, enabling me to run as an independent candidate for the Legislative Council in the state election held on 8 March. Richard Lugg, our Vice President, has acted as President in my absence. I would like to thank him very much for doing so. Others, such as Murray Hindle and Dinny Laurence, took on extra tasks to share the load. So it has been a busy time for all. Thank you to all.

The final Legislative Council vote having now (finally!) been concluded, I have returned as President.

I look forward to seeing members (and supporters) at the General Meeting to be held at 2pm on 21st May at Citiplace (Perth railway station concourse).

Where to from here?

This is an opportune time to talk about our future plans. For the last year or so the committee has considered various means to pursue our central aim of fostering community, governmental and parliamentary discussion of how to achieve reasonable changes to our Voluntary Assisted Dying Act that might expand the categories of people eligible to choose a peaceful death.

The most obvious changes would be to:

1. Remove the arbitrary and irrational stipulation that to qualify, a person must have only 6 months to live (12 months for a neurodegenerative condition) - instead, as has been approved in the ACT, it should be enough that the person is approaching the end of their life, and finds their suffering to be unacceptable; and
2. Follow the leads provided by Canada (and Quebec in particular) by permitting a person who has been assessed as eligible for VAD but who subsequently loses capacity (for example, because of the effect of medications or because of dementia) to receive an assisted death despite that capacity loss if they have previously signed an effective Advance Health Directive in appropriate terms.

Various other reforms should also be adopted.

One of those would be to compel aged care service providers to permit residents or patients to receive VAD services within the premises, even if the operators object. Further, providers should be forced to provide their VAD policies ahead of time to those considering taking up residence (whether temporarily or longer-term). These commonsense provisions have been operative in some other states for years now.

Over the last 6 months or so we have taken every opportunity to engage with media on the need for genuine and real consideration of VAD reform.

Our previous Health Minister was impervious to our efforts. The Premier failed to take up our request for a further parliamentary joint select committee to assemble the local, interstate and overseas evidence regarding reasonable reforms.

So, where should we go from here? And how should we get there?

One welcome change is that we now have a new Health Minister (well, three of them, really, but one with whom this buck must stop - Meredith Hammat). We are in the process of seeking an early meeting with her.

Through the efforts of Julie Cinanni and Dinny Laurence, we have been exploring the option of engaging a professional firm to guide and advise us in our continued campaign for reform. The cost would be significant and would require substantial fund-raising.

Steve Walker, President

2025 update of the Dying with Dignity WA website

At first glance, the DWDWA website looks much the same as always, but it has had a major overhaul. It still looks familiar and is easy to navigate but there is a lot of interesting new content and information.

HOME

Click on 'How to access VAD' for guidance about who is eligible for voluntary assisted dying and who can help you through the process.

Click on 'How VAD became law in WA' to remember the historic campaign from 2017 until 10th December 2019, the date on which VAD became a lawful end of life choice in WA.

News, stories and reflections can also be found on this page.

ABOUT/

The content of some of the tabs under this heading has changed.

'Our Organisation' lists the current members of the DWDWA committee with photos to match.

Under **VAD Conference 2024**, you can read a summary of the official report of VADCON24, the second annual trans-Tasman voluntary assisted dying conference hosted by Go Gentle Australia in Brisbane in October 2024. The summary provides interesting and informative insights into many aspects of VAD, including the ways it is evolving or needs to evolve. The summary is printed with the permission of GGA.

Under **State Election 2025**, you can read about the importance of the recent election in Western Australia and how DWDWA plans to work for the improvement of the VAD Act to provide more equitable access to this lawful and compassionate end of life choice.

The **2025 Survey Results** page gives the results of a survey about four key reforms to VAD laws proposed by DWDWA. The support from the six political parties and three independent upper house candidates who responded averaged 76% across all questions.

RESOURCES/

Of the ten tabs under this heading, the first five are self-explanatory. They have been updated but there are no significant changes in content. The second five are detailed below:

The **VAD Board Reports** page provides a summary of the VAD Board's annual reports about the first three years of VAD's operation in WA. The reports include recommendations for statutory changes to the VAD Act and non-statutory process changes that are necessary. There is a separate article in this newsletter about the third VAD Board annual report for the year ended 30th June 2024.

The **New AHD** page gives detailed information about advance health directives, **a sample with suggestions about how to complete the AHD form**, and extensive answers to frequently asked questions.

You can find the new look DWDWA version of the Department of Health AHD form if you scroll down to '**Click for DWD interactive AHD form**' (white type on purple background). The Department insisted that DWDWA remove the DOH insignia from its version of the AHD in order to 'prevent confusion' with the official form.

In response to general feedback about some of the problems with the official form (including from DWDWA), the Department is currently undertaking a review. We hope that the new form will be made shorter and more user-friendly, including by the removal of the long section about research, which has no place in an AHD.

Dementia is a new page. In it you will find DWDWA's position on how ways might be found to provide access to VAD for those suffering from dementia and other neurodegenerative conditions leading to loss of capacity.

The **Review of VAD Law Stage I** is a new page that outlines the result of the first mandatory review of the 'operation and effectiveness of the VAD Act'.

The new **Review of VAD Law Stage II** provides a summary of a second review commissioned by the Department of Health and conducted by a research team from the Queensland University of Technology (QUT).

The priority issues identified by QUT were:

1. the lack of public knowledge about the VAD system and difficulties associated with connecting to the system;
2. that individuals and institutions, either intentionally or otherwise, are impeding a patient's ability to access VAD; and
3. that the current workforce may not be able to meet the future demand for VAD.
4. The other issues, key themes and recommendations set out on the Stage II review page make interesting reading.

The remaining tabs on the website are self-explanatory.

DWDWA thanks Shayne Higson for her invaluable support in updating the website.



DINNY LAURENCE

Summary of the Go Gentle Australia VAD Conference 2024

With the permission of Go Gentle Australia, Dying with Dignity WA is pleased to provide this summary of the official report of VADCON24, the second annual trans-Tasman voluntary assisted dying conference held in Brisbane in October 2024.

The three-day conference was hosted by GGA and delivered in partnership with VADANZ (the peak body for VAD health professionals) and QUT's Australian Centre for Health Law Research. It was attended by a number of important stakeholders in different aspects of VAD, including health professionals, policymakers and researchers.

This summary does not purport to cover the full range of discussions, research and insights from the conference. The full report can be found on the GGA website at https://www.gogentleaustralia.org.au/2024_conference_report

Key themes

The over-arching theme of the conference was 'Access and Equity' with four underlying sub-themes:

VAD is not yet an established end of life option

Notwithstanding the growing demand for VAD, public awareness and health professional participation need to be increased for VAD to become fully established as an end of life choice.

There were promising signs that palliative care and VAD were not at odds with each other, with the view of the overwhelming majority of palliative care workers being that VAD had no effect on or *actually increased* the demand for palliative care.

Greater support needed to secure future VAD workforce and services

The sustainability of the VAD workforce is a concern in all jurisdictions. Ways to ameliorate this were discussed, including by encouraging the increased participation by health professionals through

- appropriate remuneration;
- the possible simplification of the VAD process and training and adding VAD modules to university curricula; and
- augmenting participation in the VAD process by nurse practitioners.

Removing limits on VAD discussions would improve patients' experience

Conference participants agreed that open discussions about VAD were essential to high quality VAD care, which would be improved by removing:

- the limits on such discussions imposed by the 'Telehealth' restrictions under the Commonwealth Criminal Code; and
- the 'gag clauses' in Victoria, South Australia and New Zealand.

People seeking VAD continue to face inequities of access

The factors that affect a person's access to VAD include

- the time to death prognosis eligibility criterion. The conference favoured the ACT criterion that the person's condition must be 'advanced, progressive and expected to cause death' and that the person must be 'approaching the end of their life';
- the likelihood of losing capacity;
- where the person is cared for, especially if the person lives in an aged, hospice or palliative care facility that is opposed to VAD;
- where the person lives, since the current residency requirements can mean otherwise eligible people are denied access to VAD on the basis of the location of their care.
- in some states, including Western Australia, access to VAD in remote regional areas is more limited*.

*Note added by DWDWA

The Program highlights can be found on slide 6 of the report.

Research highlights are on slide 7.

Survey

At the end of the conference, delegates were asked to rank their priorities in relation to three key issues:

- (1) VAD Reform
- (2) What would improve the experience for people seeking VAD; and
- (3) How can we boost the number of VAD health professionals.

Survey Results

The results and analysis of the survey can be found on pages 8 and 9 of the report.

The top five responses in relation to each of the key issues are set out below in order of ranking:

Reform

1. Allow use of telehealth and electronic communications in VAD practice.
2. Standardise or remove timeframes to death.
3. Raise awareness and improve understanding of VAD.
4. Increase the number of VAD health professionals.
5. Remove state residency requirements.

Improve the VAD Experience

1. Reduce or remove limits on open discussion.
2. Increase awareness and understanding of VAD and end of life.
3. Standardise or remove timeframes to death.
4. Easier access to VAD health professionals.
5. Reduce process length and complexity.

Boost the number of VAD health professionals

1. Improve remuneration.
2. Increase awareness / acceptance of VAD.
3. Greater collaboration between VAD and palliative care.
4. Reduce administrative complexity.
5. Increase peer support structures.

The analysis of the survey results shows:

The most common reasons people leave the VAD workforce are

1. Workload
2. Remuneration
3. Emotional toll

80% of respondents see themselves working in the VAD field in five years.

69% believe that prognosis timeframes (e.g. 6-12 months to live) are an unnecessary safeguard.

64% have personally, or via a close colleague, been aware of a VAD patient obstructed or denied access to VAD by a non-participating institution.

86% agree that residency requirements should be standardised now VAD is legal everywhere except the NT.

73% support a patient already approved for VAD being able to nominate someone to provide final consent in the event they lose capacity.

DWDWA is grateful to GGA for giving its permission for this summary to appear on the DWDWA website and in its Autumn Newsletter.

VAD Board Annual Report for the year ended 30th June 2024

The third VAD Board Report for the year from 1st July 2024 to 30th June 2024 (the **2024 Report**) was published in November 2024. As always it made interesting and illuminating reading.

As set out in the preceding article, Dying with Dignity WA was disappointed by the failure of the mandated review of the Act to consider any changes to the legislation, even those recommended by the VAD Board – the statutory body one of whose functions is to monitor the operation and effectiveness of WA's *Voluntary Assisted Dying Act* (the **Act**). It remains to be seen whether the newly elected Labor government, with a third term safely delivered to it in the recent election, will find the courage to have a comprehensive and independent review of the Act next time round.

The 2017 -2019 campaign to legalise voluntary assisted dying demonstrated that personal stories are the most powerful way to persuade members of parliament of the need for change. It was therefore encouraging to note the increase in the number of people who wrote to the Board about their experiences of VAD during the third year of this being a lawful end of life choice in Western Australia.

The Board acknowledges the positive feedback about VAD but also notes that *"It is evident from the Personal Reflections received that where patients face barriers or are unable to access voluntary assisted dying as an end-of-life choice it is distressing for patient, family, care coordinators, participating practitioners and treating teams"*.

These personal reflections (de-identified) can be found on pp 7 – 12 of the 2024 Report and on the DWDWA website under 'Stories' at https://www.dwdwa.org.au/personal_reflections

Concerns raised in 2023-24

In 2023–24, concerns were raised with the Board "from patients, their families, participating practitioners and statewide service providers,

regarding barriers to access to voluntary assisted dying for patients receiving care within the WA health system, including public and private hospitals providing public health services as contracted health entities".

A full list of these concerns can be found on pages 53 and 54 of the 2024 Report. These are some of them:

- First Requests and requests for information on VAD being "ignored, refused or not recognised";
- delays in referring a patient to an appropriate health service provider (HSP) or care navigator;
- poor communication with patients and their families and between treating teams and the patient's Coordinating Practitioner;
- conscientious objection complicating patient access to VAD;
- restricted sharing of information, despite patient consent;
- lack of information about private hospitals providing public health services that have an institutional objection to voluntary assisted dying.

In addition, the Board:

- notes that "many patients are beginning the voluntary assisted dying process late in the course of their illness which may indicate a lack of awareness and understanding of voluntary assisted dying as an end-of-life choice";
- "was disappointed to hear of cases where health practitioners provided inaccurate or delayed responses to requests for information on voluntary assisted dying to patients and family members";
- "reviewed cases where patients and practitioners appeared to hold differing views on the language that would constitute an unambiguous First Request";

It seems from the above that some barriers to accessing VAD can arise because patients do not understand the process, and this is understandable. More worrying is that health practitioners may not properly understand it

either or may deliberately obstruct access to VAD by providing inaccurate information or delayed responses. It is also worrying that “inadequate access to practitioners presents a risk to the sustainability and operation of voluntary assisted dying in Western Australia”.

On the basis of its findings the Board recommends specifically that “the Department of Health develop and implement strategies to improve public awareness of voluntary assisted dying as an end of life choice for eligible Western Australians, including practical patient guidance on asking for information and making a First Request”.

It also recommends that action is required to raise community awareness and understanding of the voluntary assisted dying process generally.

Some of these recommendations can be found in the Review Report which nevertheless concludes that the law is “working as intended” and “does not require legislative change”.

The Voluntary Assisted Dying Board Strategic Plan 2023 to 2026 (p. 56) outlines how “the Board will seek to fulfil its functions under the Act and make the most of its unique access to information, in support of the principles and intention of the Act, to ensure that voluntary assisted dying is available to all eligible Western Australians as a sustainable, person-centred, end of life choice”.

The Board’s Recommendations – including those in its submission to the Review - can be found on pages 52 – 55 of the Report.

POSTSCRIPT

Many of you will remember that at the beginning of the campaign for VAD in 2017, polls conducted independently by Roy Morgan and the West Australian each recorded community support at 88%.

Now, after three and a half years in operation, the law is well-established, but - paradoxically - the level of community awareness has fallen - not only about how to access VAD but about its very existence.

DWDWA is planning a campaign to rebuild that community support for legislative

reform to improve access to VAD. The Board’s recommendations provide a unique opportunity to work with the Department of Health and government to achieve this objective.

DINNY LAURENCE

End of Life Doulas in Western Australia

A ‘doula’ is a non-medical professional who supports another person through a significant health-related experience. An ‘end of life doula’ provides such support in relation to all aspects of the end of life process, including death and dying, not only to the person most affected but to their families and loved ones. The doula’s guidance is dictated by the person’s own needs and wishes, extending from practical advice about wills, advance health directives, and enduring powers of guardianship and attorney, to deeply personal emotional support. Since the passage of the *Voluntary Assisted Dying Act 2019*, this support is also provided in relation to VAD.

There are not many end of life doulas in Western Australia, and the DWDWA committee was privileged to meet one of them at a recent committee meeting. She is Janette Parsons-Smith - and as she told some of her stories many of us were moved to tears.

Janette has agreed to be the guest speaker at the DWDWA general meeting to be held at Citiplace (upper concourse, Perth railway station, cnr Wellington and Barrack Streets) at 2pm on 21st May. We very much hope you will be able to come along to meet and listen to Janette and hear about the wonderful services she provides”.

This is a short introduction to who she is and what she does.



This paperwork is extremely important to have in place for you and it offers a peace of mind for your loved ones.

My motto through life has always been "I Care"

Let me care for you and your loved ones with love and compassion, as end of life approaches.

JANETTE PARSONS-SMITH

Mob: 0412 217 291

Email: jps108@westnet.com.au

Hi, I'm Janette

Let me introduce myself.

I am a Fully Qualified End Of Life Doula trained through the Australian Doula College.

I offer services of Love, Support and Compassion as you and your family journey through the end-of-life cycle.

I am a mother of four, a grandmother of nine, and, sadly, a widow to the love of my life and best friend, my husband Brian. I nursed my husband at home sadly watching his end of life happen, but also happy he was about to Rest In Love. He was my beautiful loving husband until his last breath and his legacy lives on.

I have over 10 years experience with volunteering for St John Ambulance, I am also a Justice of the Peace available to witness and sign paperwork for you and or your loved ones. (As a JP I am unable to offer legal advice)

As your Doula let me help you with your Health Directive - Your Will - The Enduring Power of Attorney - The Enduring Power of Guardianship and Funeral instructions of your choice along with applicable around your home duties to assist your loved ones.

DYING WITH DIGNITY WESTERN AUSTRALIA (INC.)

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

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If the address label on this newsletter has a **date ending in 24 (or earlier), your subscription is no longer current.** If it ends 25, your renewal is due 1st July. Life members are noted as such and don't need to pay subs, although donations are always welcome.

If paying by bank deposit, particularly at a bank, 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

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JOURNAL – ISSN 0813-5614

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