

Dying with Dignity

New South Wales



NEWS | Summer 2023/2024



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JOURNAL – ISSN 0813-5614



President's Message

The NSW Voluntary Assisted Dying (VAD) Act came into effect on Tuesday 28 November 2023. It was a day of mixed emotions – relief that the law we fought so hard for is finally available for dying people in NSW and sadness as we remembered those who fought so hard to have this law passed, knowing that they would die without having access to it themselves.

We spent much of the day at Parliament House with a press conference followed by an event to thank our key campaign volunteers and those MPs who co-sponsored or voted to support the VAD Bill.

In the weeks since the law took effect we have been assisting a number of people with their VAD applications and working with NSW Health to help them through the complex steps involved in the process.

The NSW VAD Care Navigator Service have received a significant number of enquiries, and it has undoubtedly been a challenge managing the demand for VAD, especially those urgent requests from people who have been desperately waiting to access the regime.

We have heard of some very peaceful deaths, while some people have unfortunately died before completing the process. Others have been disappointed to find that they do not yet meet the eligibility criteria.

It is still early days and we know that some teething problems are inevitable as both patients and the healthcare system navigate a very new and complex system.

We are very keen to hear the experiences of people who are going through the VAD process. This allows us to monitor how the system is working and give vital feedback to NSW Health and also to provide information and guidance to others who wish to apply.

On pages 5 and 6 we have outlined some important considerations for those seeking to apply for VAD and how to access detailed information about the process via the NSW Health website.

We are very pleased to announce a partnership with Griefline, initiated by DWD Victoria, which has created some VAD specific resources and support

groups for people who've been involved in a VAD death. They also offer a free phone counselling service for anyone struggling with grief and loss. See page 9.

On page 14 you will find a review of the final work of the late Dr Rodney Syme who played a pivotal role in the dying with dignity movement in Australia for decades and has never been one to shy away from raising challenging issues. *A Completed Life* explores the plight of those suffering dementia and the increasing numbers of frail elderly expressing a rational desire to die on their own terms rather than face increasing infirmity and the loss of their independence, sense of purpose and pleasure in their lives.

In the second half of 2023 we continued our webinar series on end-of-life issues with two excellent sessions. The first featured End of Life Doulas and the invaluable role they can play in supporting dying people and their loved ones through what can often be a difficult and confronting journey. The second focussed on the practical aspects of voluntary assisted dying featuring two VAD doctors and a care navigator from Victoria and the doctor leading the clinical side of the NSW VAD program. See pages 8 and 9. We are planning further webinars during 2024.

As always, this edition provides an update on VAD around the country and overseas. The most important local news is the recent introduction of a VAD Bill in the ACT which we hope will be debated shortly. There are encouraging signs coming from the UK and momentum also seems to be building in the USA with VAD bills before the legislature in 17 states. However, we've learned from bitter experience not to get our hopes up too much and we know that opponents of VAD are fighting harder than ever.



As always, thank you for your support,
Penny Hackett

NEWS FROM NEW SOUTH WALES

At last NSW residents have a VAD law

On Tuesday 28 November 2023 New South Wales became the final state in Australia to implement a Voluntary Assisted Dying (VAD) law.

Dying with Dignity NSW welcomed the commencement of this compassionate, end-of-life option for eligible, terminally ill residents of NSW who are experiencing intolerable suffering.

After 50 years of lobbying this important day brought mixed emotions for most advocates.

There was a huge sense of relief and feelings of deep gratitude but there was also a touch of sadness, as we remembered all of the courageous people who shared their stories during the campaign.

To mark this historic milestone, we held a press conference at Parliament House followed by a private gathering to thank our dedicated members and volunteers who worked so hard, for so long, to achieve law reform.

We thanked Alex Greenwich MP, the Independent Member for Sydney who introduced the legislation, the 28 co-sponsors of the Bill and those members of NSW Parliament who supported the much-needed law.

Our heartfelt thanks extended to the Voluntary Assisted Dying Implementation Team at NSW Health who worked so hard throughout the 18 month implementation period to prepare for the new law.



The 28 November 2023 was a day to celebrate because for many dying people the new law provides enormous peace of mind to know that they can regain some level of control and if they choose to, they will have the option to die peacefully at a time and place of their choosing.

We also took the opportunity to remember and acknowledge those courageous, terminally ill advocates who spent their last days, weeks or months sharing their personal stories to help achieve a law they would never be able to access.

Only a fraction of our supporters were able to attend the event so we chose to display some of our 3,000 “Field of Hearts” messages, just one more time, so even those who couldn’t make it, were with us in spirit.

For some terminally ill people, who had been waiting desperately for the start date to arrive, it came just in time. For others, who are still battling life-limiting illnesses, the new law will provide comfort and have a palliative effect in itself.



Janet Cohen has been on that journey since 2013 when she was first diagnosed with cancer. After successful surgery, Janet was cancer-free for two years but in 2015 the cancer returned.

Janet always knew that she would want the option of VAD, if her symptoms became unbearable, so in the absence of any legislation in Australia to give her this choice, Janet applied and received provisional approval for an assisted death at Swiss-based Life Circle clinic in 2020. She then turned her attention to campaigning for law reform in her home state of NSW while continuing her cancer treatment.

“I’m relieved that new treatments meant that I didn’t have to take up the Swiss option before VAD became available here,” says Janet.

Janet doesn’t know how long she has to live but she does know she will be applying for voluntary assisted dying as soon as she meets the eligibility criteria.

“It’s about regaining a sense of control and autonomy,” says Janet. “Having this option has given me back some feeling of agency and now I can die in Australia, instead of travelling to Switzerland. I can now have my loved ones around me and go on my terms.”

Janet Cohen graciously accepted our invitation to take part in the press conference, travelling from her home on the Mid North Coast. We knew there would be media interest but had no idea just how many interviews she would be asked to do.



Penny Hackett, Janet Cohen, Adam Searle and Alex Greenwich at the press conference

We wish to thank Janet Cohen and the other courageous people who shared their stories to mark the commencement of VAD in NSW including Mark Butler, Scott Riddle, Jacque Hooper and Judy Fullgrave.

We also extend our heartfelt thanks to the hundreds of our supporters who so generously shared their personal stories during the decades of campaigning in NSW, including the previous VAD Bill debates in 2013 and 2017 and the debates during 2021 and 2022 when the VAD law was finally passed.



Some of our courageous advocates who died waiting for VAD law reform

Calling for VAD stories

NSW was the last state to legalise voluntary assisted dying and, despite being in operation for just two months, the media are keen to report on this new, compassionate option for eligible terminally ill people facing intolerable, end-of-life suffering.

This is a very difficult thing to ask but, as many of you know, personal stories have always played an important role in our campaign for law reform and they continue to play an important role in raising awareness of the new law and understanding how the operation of the new law might be improved.

If you, or someone close to you, are intending to apply for voluntary assisted dying or have supported someone through the VAD process already, we would love to hear from you, especially if you would be willing to share your story publicly.

Either way, please contact us by emailing dwd@dwdnsw.org.au or call me on my mobile - Shayne Higson, CEO - Mob: 0428 326 358.

What we have learnt from the first few months

At the time of writing this newsletter the NSW Voluntary Assisted Dying (VAD) law has been operating for 8 weeks.

During that time we have been contacted by a number of people trying to access VAD and also family members of people who tried to access the law but died before being able to complete the application process.

As we expected, the VAD Care Navigator Service have been kept very busy, as they try to deal with the large number of calls, including many from people trying to expedite the process because they were at the final stages of their terminal illness by the time the law took effect. A number of people tried their best to hang on so they could access VAD but unfortunately they were just too unwell to get through the process and they died with palliative care.

We are pleased that we have been able to support these people at this early stage of the VAD scheme, putting them in contact with the Care Navigator Service and making sure they also have access to appropriate palliative care while working their way through the VAD application process.

We are confident that as time passes access to the new law will become more streamlined and less daunting. However, there are already lessons learned from the first 8 weeks of operation and below is some advice that might assist people considering this new, end-of-life option.

How to prepare if you want to access VAD

1. Understand the eligibility requirements

There would be many people who will be hoping that when they approach what they consider to be their end of life, they will be able to access voluntary assisted dying. Most of our readers will know that the NSW VAD law passed a few years ago and that it took effect in November last year. What you may not be as familiar with is the eligibility criteria, especially the requirement that you have a disease, illness or medical condition that is advanced, progressive and will cause death. Two doctors must confirm that death is

expected, on the balance of probabilities, within 6 months or within 12 months for neurodegenerative diseases. There have been a few cases, that we have been made aware of, where the requirement for a set prognosis has meant that the patient's request has been denied resulting in additional distress and mental suffering at a time when these people thought they would have peace of mind. Unfortunately many doctors do not feel confident giving a prognosis so rejections based on an inability to confirm the expected time to death were predictable but nevertheless very difficult to accept. If you are not found eligible, you can always apply at a later stage if your condition changes or more information about your prognosis becomes available

2. Ask your doctors for copies of your scans, tests and reports

If you have a disease, illness or medical condition that is advanced and progressive and you think that you would like to have access to VAD, at some point in the future, we highly recommend that you obtain copies of all your medical records including scans, tests and reports. If you try to access these at a later stage in your illness, it can be time-consuming and frustrating, especially if your doctor is on holiday or it is a weekend etc.

3. Ask for confirmation of your prognosis

Even if you have only recently been given the devastating news that you have a terminal illness, you can ask that your doctor, or doctors, to give you an honest opinion about your prognosis. You can say that you just want to be prepared and get your affairs in order, you don't have to mention your wish to access VAD at this stage. What you don't want is to have your doctor, who may not support your choice to access VAD, to be hesitant about providing a realistic prognosis because they know this is something that you will need to proceed through the VAD application process. Another thing to consider is that you should ask for a realistic prognosis based on the stage of your illness without taking into consideration any future life-extending treatments because you may decide that you don't want to undergo those treatments. For example, you may refuse further chemotherapy, mechanical ventilation, or feeding through a PEG tube. You cannot be forced to undergo treatments of any kind. That is your legal right, with or without a VAD law. We recommend that you ask for that realistic prognosis in writing.

4. Ask your doctor if they support VAD

Once you have a written prognosis, at a later appointment, you could ask if your doctors support VAD. Based on the experience of the past 8 weeks, it is likely that your treating doctors will be consulted about your condition and prognosis. They may not understand VAD and may even oppose it but their input may influence whether your VAD application is approved.

If your doctor does not support your choice and you have time, we would suggest getting a second opinion and maybe even changing your treating practitioner.

Over time we hope that many more doctors will sign up to provide VAD and hopefully your own doctor will be prepared to help you access VAD by doing the training to become an authorised provider.

However, most people will find that their own treating doctors are not authorised to provide VAD and we suggest that you contact the NSW VAD Care Navigator Service who can put you in touch with an approved practitioner.

5. Start the process early

The most important advice we can give people wanting to access VAD is - **DO NOT DELAY.**

The process can take some weeks or even months to complete so it is important to start the process early and make sure you have all the relevant documents and medical records available to minimise delays and stress.

How to apply for VAD

The NSW Voluntary Assisted Dying scheme has now been operative for 8 weeks and NSW Health have had a busy time dealing with an initial surge of requests for VAD and for information from patients and clinicians.

Once you have considered the advice in the previous section, if you, or someone you are caring for, wants to begin the VAD application process, please see the steps set in the diagram on page 7.

For some people, the first port of call will be their treating doctor(s). However, we know that most doctors are not authorised VAD providers and some may not be supportive of VAD.

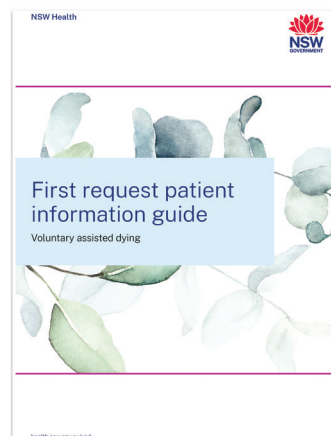
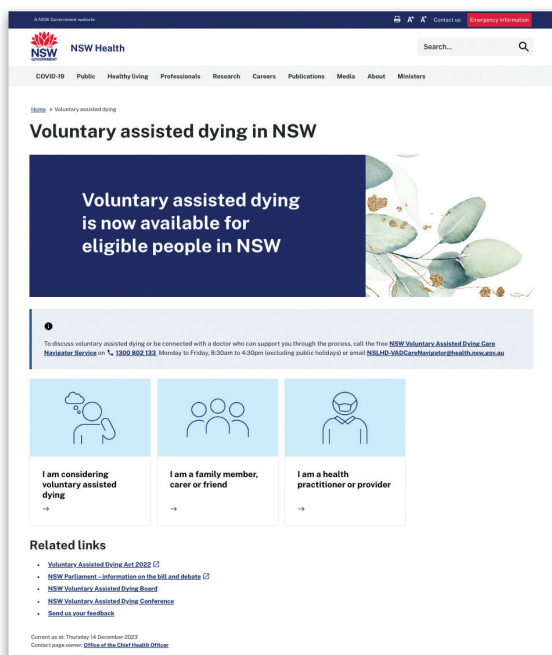
If your own doctor(s) is not a registered VAD provider, you should contact the **NSW VAD Care Navigator Service** who are trained health professionals who can help you find an authorised doctor, answer your questions and support you through each step of the process.

Contact details for VAD Care Navigators:

- **Call: 1300 802 133** Monday to Friday, 8:30am to 4:30pm (excluding public holidays)
- Email: NSLHD-VADCareNavigator@health.nsw.gov.au

NSW Health VAD Resources

The NSW Health VAD website at - <https://www.health.nsw.gov.au/voluntary-assisted-dying> has information on the steps involved in making a request for VAD. They have also produced a detailed patient guide with the nuts and bolts of the process. It is a vital resource for anyone actively seeking VAD and it can be found using this link - <https://www.health.nsw.gov.au/voluntary-assisted-dying/Publications/first-request-patient-guide.pdf>



NSW Health



Voluntary assisted dying in NSW

There are **11 steps** in the voluntary assisted dying process in NSW. You can pause or stop the process at any time.



The NSW Voluntary Assisted Dying Care Navigator Service

is a phone line to answer questions about voluntary assisted dying.

The Service will support everyone including patients and families.

Call **1300 802 133**
Monday to Friday
8:30am to 4:30pm.

This is a summary of the key steps of the voluntary assisted dying process under the Voluntary Assisted Dying Act 2022. This summary is indicative only and does not cover all the scenarios that might arise during a patient's individual voluntary assisted dying process.

DWD's end-of-life webinars

During 2023, as part of our goal to educate our supporters and the general public, we held a series of online webinars on end-of-life topics. We reported on the first two in our previous newsletter and are delighted to report on the others below.

End of Life Doulas - Bridging the gaps in care

Over the past century, death has become more medicalised in our Western society. The truth is death is not a medical event, it is a profoundly personal, individual, family and community event.

Where once we would have cared for our ageing and dying at home, these days our elders are cared for in aged care facilities and hospitals, which can often contribute to an isolated, lonely and disempowered end of life.

When someone receives a diagnosis of a life-limiting or terminal illness or is ageing, it can be a lonely, confusing and confronting time for them and those close to them. There is often so much to manage and many choices to make. Knowing what options are available and feeling empowered to make decisions can make a significant difference to all involved.

On Wednesday 2 August we hosted our third webinar on [End of Life Doulas - Bridging the gaps in care](#) with special guest speakers – Helen Callanan, Jancine Hurst and Carolyn Vaughan.

We had over 1,100 registrations and approximately 330 participants with many of those who missed the live event catching up on the recording.

We all came away from this webinar with a greater understanding of the potential support that can be provided by an End of Life Doula.

For information about where to find an End of Life Doula or how to become an End of End Life Doula or to watch the recording of this webinar visit our website - https://www.dwdnsw.org.au/end_of_life_doulas_webinar

Finding an End of Life Doula

Here are links to a number of websites with contact details for End of Life Doulas in NSW

Preparing the Way preparingtheway.com.au

End of Life Doula Directory
endoflifedouladirectory.com.au

Australian Doula College
australiandoulacollege.com.au

Natural Death Advocacy Network ndan.com.au

Becoming an End of Life Doula

If you are interesting in becoming an End of Life Doula you can find out more about the training programs at the *Preparing the Way* website.

Preparing the Way - preparingtheway.com.au/end-of-life-doula-training/

For more information, email them directly at enquiries@preparingtheway.com.au

End of Life Doulas - Bridging the gaps in care

RECORDING AVAILABLE ON OUR WEBSITE



Helen Callanan



Jancine Hurst



Carolyn Vaughan



UNDERSTANDING THE OPTION OF VOLUNTARY ASSISTED DYING

Webinar recording available on website

(Clockwise - Dr Cam McLaren, Dr Greg Mewett, Dr Wade Stedman and Nicky Stitt)

Dying with Dignity
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Understanding the Option of Voluntary Assisted Dying

On Wednesday 18 October 2023 we hosted the final webinar in our series on end-of-life issues for 2023 titled - [Understanding the Option of Voluntary Assisted Dying](#). We had four very experienced guest speakers - Victorian VAD providers, Dr Cam McLaren and Dr Greg Mewett; Victorian VAD Care Navigator, Nicky Stitt; and the Clinical Lead for the implementation of VAD in NSW, Dr Wade Stedman.

Our guest speakers provided important information including who would be eligible for Voluntary Assisted Dying (VAD) in NSW and who won't be; how people will be supported through the application process by VAD Care Navigators; what it means for dying individuals and their loved ones to have this compassionate, end-of-life

choice; and important differences between the NSW VAD law and interstate laws.

Our audience raised some tough questions including why certain people suffering at the end of their lives won't qualify for VAD. We were extremely grateful that our presenters did not shy away from discussing these difficult scenarios. We all know how important it is to have open and honest conversations about every aspect of end-of-life care and decision-making. We are incredibly fortunate to have such caring and dedicated healthcare professionals involved in our VAD schemes, experts who are also willing to share their knowledge and experience to help the community understand the option of voluntary assisted dying.

The recording can be viewed on our website at - https://www.dwdnsw.org.au/news_vad_webinar

Griefline

Free Grief and Bereavement Support for Family and Friends of those using VAD

Dealing with grief can be very challenging at the best of times. Experience from other states has shown that the death of a loved one who uses VAD can raise some unique issues for those left behind, both before and after death. This has led to families and friends seeking support from those who are familiar with the VAD process.

With Victoria having the first VAD law, Dying with Dignity Victoria have partnered with Griefline to develop some VAD specific resources and run support groups to connect those who have experienced VAD with a loved one. These are available to residents in all states and territories.

Griefline also provides free and confidential telephone support staffed by trained counsellors, for anyone experiencing loss or grief.

If you are struggling with these issues we urge you to make contact with Griefline using the following links:

- Telephone support line: Call **1300 845 745** between 8am and 8pm, 7 days a week (AEDT)
- Information about Support groups: [Griefline webpage](#) and [Factsheet](#)
- Guide to coping with grief after VAD: [Coping With Grief After Voluntary Assisted Dying: A Guide For Family And Friends](#)

NEWS FROM AROUND THE COUNTRY

Thank you to our interstate DWD colleagues for providing the information used in these reports.

Victoria

Review of the operation of Victoria's Voluntary Assisted Dying Act 2017: A review of the first four years of operation of the VAD Act is currently being undertaken by the Centre for Evaluation and Research Evidence (CERE), at the Victorian Government Department of Health. The review commenced in July 2023 and although there were no terms of reference provided, individuals with past involvement with VAD are invited to make written submissions. After the review concludes in June 2024, the report, including key findings, will be tabled in both Houses of Parliament and a summary report will be made available. As the legislated five-year review is confined to operational issues, it will not consider changes to the legislation itself (e.g. changes to eligibility criteria are out of scope for this review). Submissions close on February 23.

Griefline VAD Support Group: The first group was successfully run over 6 weeks with weekly 2-hour sessions. Another group will be run soon. Interestingly all participants were from rural areas.

Dr Rodney Syme's book - 'A Completed Life: DWDV's new President, Jane Morris and board member, Michelle Hindson, have been very busy promoting this newly published book. It has been extremely well received with terrific comments being made by Marshall Perron and Peter Baume. Sales of the book through the DWDV website are doing well. A press release sent to newspapers, radio and television resulted in an hour devoted to the subject of VAD and Dementia on ABC Radio in the 'Conversation Hour'. The producer of the program said they were inundated with calls and texts and plans to do another program in early February.

AGM: The guest speaker at DWDV's AGM was journalist Michael Bachelard who spoke passionately about the VAD and Dementia topic, Dr Rodney Symes' book, and the issues we consider problematic with the Victorian VAD Act.

South Australia

VADSA Witness Program: Many people become isolated as their illness progresses and it becomes difficult to identify witnesses required for the written request. Following Victoria's lead, VADSA is also providing a volunteer witness program. All witnesses have completed a two hour training program, signed a confidentiality agreement and provided a police check. Volunteers and the health professionals involved all report positive outcomes from the program.

VAD Act Comparison: Anne Bunning from VADSA produced a valuable comparison of state VAD legislation. It is available as Factsheet 45 on the VADSA website.

Relationship with SA Health VAD team and Review Board: VADSA has a strong working relationship with both the VAD team in SA Health and the VAD Board. They have regular two way briefings and were part of the competition video for the Premier's Award for Excellence in Health won by the VAD team. VAD Board Member, Ass Prof Mel Turner, addressed the VADSA AGM.

VAD Annual Report tabled: Covering the first five months the Report showed that 45 people with a VAD Permit died during that period, 39 by using the VAD substance, 28 by self-administration and 11 by practitioner administration. Most people died at home, although 18 died in hospital, with anecdotal evidence that some people chose to move from home to hospital at a late stage, considering family carers.

The Territories

Northern Territory

Eight months after its right to legalise Voluntary Assisted Dying was restored by the federal parliament, the NT Government finally moved to act on voluntary assisted dying law reform. In mid 2023 an Expert Advisory Panel was established to provide an independent report to the Government. The Expert Panel is continuing its discussions with Territorians to find out what people want in the proposed VAD legislation in the NT. Their report is due in July 2024.

Australian Capital Territory

The ACT moved more quickly once the Restoring Territory Rights Act 2022 was passed by the Federal Parliament in December 2022.

Extensive community and stakeholder consultations were conducted to shape the legislation of the Voluntary Assisted Dying Bill 2023 and a parliamentary committee inquiry will deliver a report before the VAD Bill is debated.

If the Bill passes, the government will spend 18 months setting up the necessary systems and safeguards for the legislation's implementation, ensuring that VAD becomes a legal option for eligible people by the end of 2025.

Two notable differences to existing VAD laws are:

- A person who meets all criteria is eligible for VAD regardless of how soon a health professional expects them to die (provided they meet all other eligibility requirements).
- There is no requirement for a minimum number of days between the first and final request during the VAD application process.

Tasmania

In July 2023, the Tasmanian Department of Health published its first [Report on the End-of-Life Choices \(Voluntary Assisted Dying\) Act 2021's operation in its first six months](#). As expected, the report concluded that the regime is operating effectively. It reported that of the 90 people who contacted the VAD Care Navigator Service - 65% had cancer and 12% had neurodegenerative diseases; 47 requests were made; 27 people were authorised to receive the lethal substance and 16 people died a voluntary assisted death.

As with other states, the majority of people requesting VAD (74%) were receiving palliative care, dispelling the myth that people seek VAD due to their inability to access palliative care services.

DWDTAS strengthened its close relationship with Palliative Care Tasmania when President, Hilde Nillson met with their CEO and their education officer late last year. They intend to explore collaboration in a number of projects in 2024.

Queensland

During 2023 Dying with Dignity Queensland focused on continuing to get the word out about voluntary assisted dying in Queensland. They provided information sessions to the public for Dying to Know Day, to NDIS trainee carers, and to various clubs. They were excited to get some new volunteers across the State, and to build their capacity to reach more remote areas.

The guest speaker at DWDQ's AGM was Lesley McLeod, Assistant Director of Nursing at QVAD Care Navigator Service. Lesley gave a moving and lively account of the first few months of VAD in Queensland.

DWDQ engaged with some key local organisations in person or by Zoom:

- o Palliative Care QLD with plans to run joint education sessions
- o Griefline (the national grief support resource)
- o Caxton Legal Service on Advance Care Plans
- o Clem Jones Group (a close ally) re-identifying strategies for 2024 including working with Aus/NZ groups on major concerns such as Telehealth.

Western Australia

In late 2023 Dying with Dignity WA was heavily engaged in their submissions to the upcoming review of the WA VAD Law and to the ACT's Inquiry into their VAD Bill.

DWDWA's President, Steve Walker did include the issue of dementia and VAD in both submissions and he hopes that work will be a useful starting point for the first National DWD Dementia Working Group meeting.

Steve Walker was also pleased to have developed a good relationship with WA Independent MP Kate Chaney who will soon introduce a private member's Bill to Federal Parliament to try to address the Telehealth issue that is impacting access to VAD. Chaney hosted a briefing for federal MP's where Professor Ben White and Dr Cam McLaren provided expert presentations.

WHAT'S HAPPENING OVERSEAS

Canada

Canada continues to be the epicentre of developments in voluntary assisted dying around the world. Those suffering from only a mental disorder are due to become eligible for medical assistance in dying (MAiD) in March 2024 and the fevered debate about that highly contentious matter continues unabated. The controversies about the absence of a “time to death” also continue. There have been reports from opponents that some people have been able to access MAiD because they were not able to receive adequate housing and social support, but these reports must be treated with caution. Earlier this year the Conservative opposition introduced a bill into parliament to disallow extending MAiD to those with only a mental illness, but it failed to pass.

Quebec (which operates under separate VAD legislation from the rest of Canada) appears to have the highest proportion of assisted deaths in the world, with seven per cent of deaths being via MAiD. This is far higher than in any other country, including the Netherlands, where the figure is four per cent. The government has become nervous about the numbers and has issued an instruction to practitioners to put the brakes on, to take longer over the process and to strictly adhere to all protocols. In June 2023 Quebec relaxed its VAD laws to permit people with Alzheimer's and other serious incurable diseases to apply for MAiD before their condition got so serious they no longer had capacity. There was a lot of confusion about the new provisions with a lack of clear protocols about when the law applied. This is now being addressed.

There has been an ongoing dispute between some Catholic healthcare facilities and the various provincial governments about such facilities refusing to carry out MAiD. In some cases, the government has forced them to do so on pain of withdrawing funding. A recent survey showed that a clear majority of Canadians believe that publicly funded organisations should be compelled to offer MAiD. St Pauls Catholic Hospital in Vancouver was one of the offenders and was ordered to provide alternative premises where MAiD could occur. A

lesson perhaps for us here in Australia.

Health Canada has released its fourth Annual Report for the calendar year of 2022. It showed that growth in the number of MAiD deaths continues. In 2022 there were 13,241 such deaths, accounting for 4.1% of total deaths, that number representing an increase of 31.2% over 2021. The total number of MAiD deaths since the commencement in 2016 is 44,958. In relation to the debate about whether there are too many people whose deaths are not “reasonably foreseeable” being given MAiD, the Annual Report tells us that only 3.5% of MAiD deaths were for cases where death was not reasonably foreseeable. The vast majority were cases such as cancer, pulmonary disease and heart disease where the prognosis is more easily determined.

USA

Momentum for VAD seems to be building in the USA. In eight states VAD bills from 2023 continue to progress while in nine additional states new VAD bills have already been introduced in 2024. VAD is currently legal in ten US states plus the District of Columbia.

In 2021 the Californian End of Life Option Act was amended to allow the mandatory waiting period between the two oral requests for VAD to be reduced from 15 days to 48 hours. This has resulted in a 47% jump in prescriptions for VAD medication.

In New Jersey DWD campaigners are planning a suit to have the residency requirement for accessing VAD in New Jersey overturned. This could be very significant because of its proximity to states where VAD is not yet legal.

At its recent conference the American Medical Association (AMA) considered dropping its opposition to VAD but resolved to retain it. However, it did resolve to examine the decriminalisation of VAD for doctors who administer it, and to look at a change of terminology from “assisted suicide” to “medical assistance in dying”. Other medical peak bodies in the US have dropped their opposition or have decided to take a neutral position.

France

In France things have moved along since President Macron announced after his re-election in 2022 that he would like France to have a voluntary assisted dying regime like Belgium's. He established a Citizens' Convention to make recommendations on a system. He said that France must improve the availability of palliative care and there would be a draft VAD bill by the end of the northern summer. The bill would build on the work of the group of 184 randomly appointed French citizens who have debated the issue since December 2022. They concluded their work recently with 76% of them saying they favoured allowing some form of assistance to die, for those who want it. Predictably the medical establishment is against it.

United Kingdom

In the UK the debate continues with a quite large volume of favourable media coverage, including many stories about Britons who have resorted to going to Switzerland. There continues to be a high level of public support for VAD, with a survey conducted in 2023 finding that two-thirds of religious people in the UK support VAD. But the government has totally stalled on it and is unlikely to progress until there is a change of government, very likely at the next general election. On a brighter note, the Crown Prosecution Service has made it clear what it thinks about the urgency to introduce VAD laws. It said that there is "no public interest" in prosecuting people who assist their loved ones to die or engage in an unsuccessful suicide pact as long as the "victim" had reached a voluntary, clear, settled and informed decision that they wished their life to end and the actions of the "suspect" may be "characterised as reluctant in the face of significant emotional pressure due to the victim's wish for their end of life."

Ireland

The Irish parliament is currently conducting a committee inquiry into a possible VAD bill for Ireland. It has heard from many witnesses, both for and against, including experts from Australia. There is solid support for VAD among the public. However, most of the professional bodies and, of course, the Catholic Church are opposed. The committee will report back in early 2024.

Isle of Man

The Isle of Man legislature has passed a VAD bill through to the next stage of debate. Advocates are hoping that if this bill finally passes, it will constitute a fillip to the stalled campaign in the UK. The main palliative care provider in the Isle of Man says it will not stand in the way if VAD is legalised.

New Zealand

New Zealand has published a report on the first year of operation of its End of Life Choices Act. In that period there were 257 deaths, constituting fewer than 1% of all deaths. Those 257 deaths were the outcome of 661 applications, 399 of whom were found eligible. Some died before they were able to take the substance. New Zealand has quite a strict dying with dignity law which specifies that a person only qualifies for a VAD if she/he has an expected life span of less than six months. In Australia most states have the same requirement but allow a 12-mth prognosis for neurodegenerative diseases.

VAD practitioners in New Zealand have identified problems with the restrictiveness of the regime. To be specific, they have found they are unable to help those with neurodegenerative diseases such as MND, Parkinson's and MS, because even though those who have those diseases suffer appallingly sometimes for years, it is difficult to predict with certainty that they have six months or less to live. The other category of neurodegenerative illness that is not covered is dementia because of the likelihood of loss of capacity at the time when it can be said that the person is six months from death.

The Act is to be reviewed in 2024 and N Z's End of Life Choice Society, intends to recommend reinstatement of the original wording proposed by the law's sponsor David Seymour, which he was forced to drop in order to get the legislation passed. The original wording was "suffering from a grievous and irremediable condition" with no specification as to expected time to death. They will also urge the government to consider allowing dementia patients to make a request for VAD via an advance care directive. Alternatively, they suggest allowing dementia sufferers to access VAD while they still have capacity. These problems are not confined to New Zealand, and reviews here will also have to face up to finding solutions.

BOOK REVIEW - 'A COMPLETED LIFE'

'A Completed Life'

By Dr Rodney Syme, *Dying With Dignity*
Victoria, 2023.

Available from DWD Victoria for \$25 for the print version and \$9.99 for the electronic version. <https://www.dwdv.org.au/store/>

Dr Rodney Syme died in 2021 at the age of 86, four months after the death of his beloved wife, Meg, who had advanced Alzheimer's disease and whom Rodney had cared for in the last years of her life. Rodney was one of the pioneers of voluntary assisted dying in Australia. As a specialist urologist, he had the medical knowledge to advise and help people at the end of life. He was selfless and determined in his advocacy for VAD in Australia and the fact that Victoria got a VAD law in 2017 was due in no small measure to his efforts. He spent endless unpaid hours supporting people and having the necessary conversations about their options when they were at the end of life.

Rodney was also a highly skilled researcher and writer and published many articles about VAD as well as three wonderful books - 'A Good Death', 'Time to Die' and this latest book, which was published posthumously by DWDVIC. 'A Completed Life' contains tributes to Rodney by people who understood his huge contribution, such as Andrew Denton, Rodney's family and

Michael Bachelard, a journalist with *The Age*, who has written so movingly about VAD.

Rodney's first two books were about the need for VAD laws, but this one goes further. He makes a powerful argument that there are two categories of people who are not covered by the existing Australian VAD laws: people with dementia and those who have had a "completed life".

This notion of a "completed life" is gaining traction - there is a movement in the US called "The Completed Life Initiative" (<https://completedlife.org>). Rodney defines it as a life that no longer has purpose or pleasure. A person who has a completed life will generally be elderly, they will have multiple physical infirmities and limitations which make it hard for them to lead an independent life and to enjoy all the things that defined them as people. They will be able to look back on a full life, a life well led in which they have experienced many of the elements which make a "good life", such as work, family, friends, and contribution to the community.

Once an elderly person becomes frail and dependent, even though they may not have a terminal disease, they can only look forward to further deterioration and increased dependency. Many such people will articulate a wish to end their lives before they hit the horrors of nursing homes and/or dementia. But there is no help for them from existing VAD regimes.



Rodney argues that such people would be capable of making a well-informed and persistent and rational request to have assistance to die but that would be in vain. In fact, they would risk being labelled mentally ill and forcibly delivered into the “medical machine”. *The Completed Life* is full of personal stories about such people, stories which vividly illustrate the concept of the completed life and the rationality of asking for help to die.

The book also provides a well-documented account of the terrible shortcomings of the aged care system and the awful plight, especially of people with dementia who are confined – Rodney says “imprisoned” – in aged care facilities. He knows a lot about dementia, having nursed his wife, and he is scathing about the carelessness with which institutions and indeed, society as a whole, deals with people with dementia, especially how badly their physical pain and existential distress is managed. He makes a powerful argument for allowing those with early-stage dementia to make requests for VAD via an advance care directive while they still have capacity.

This is a powerfully written and compassionate book. Essential reading for everyone who cares about choice at the end of life.

This review was written by Dr Liz Jacka

OTHER NEWS

New Podcast Series

The Australian Centre for Health Law Research at QUT has played a vital role in the passage and operation of VAD laws in Australia and providing valuable resources on the complex laws surrounding end of life. Led by Professors Ben White and Lindy Willmott their advice and research on VAD has been and will continue to be invaluable to the healthcare and legal sectors, policy makers and the community.

Their team have recently produced a 10 episode podcast series featuring experts discussing their research on key aspects of VAD. You can access the “Learn Me Right - VAD Series” podcast here - <https://research.qut.edu.au/voluntary-assisted-dying-regulation/impact/>

Restrictions on Telehealth - Update on the “carriage service” problem

We have written previously about a federal law which makes it a crime to use a “carriage service”, including the internet, phone and email, to access, transmit or make available “suicide related material”. This law limits access to VAD consultations by telehealth and potentially criminalises the actions of doctors helping patients exercise their legal rights under state VAD laws. People in regional and remote areas are particularly disadvantaged.

This problem would be easily fixed by amending the commonwealth Criminal Code to exclude actions taken under a state VAD law. This has been considered by the federal and state attorneys general, but we see no signs of action, despite lobbying from professional medical bodies and DWD groups around the country.

Dr Nick Carr, a VAD provider and board member of DWD Victoria attempted to resolve the problem through action in the Federal Court, by seeking a judicial declaration that VAD is not “suicide” for the purposes of the carriage service laws.

Unfortunately, last November the Federal Court ruled against Dr Carr and determined that the definition of ‘suicide’ retained its “ordinary meaning” of “the act or action of taking one’s life” and does extend to voluntary assisted dying.

This is incredibly disappointing, leaving both doctors and patients in an uncertain position and impacting the ability of patients to access a legal medical treatment.

Because the federal law overrides state VAD laws, this problem can only be resolved by federal parliament with the support of the Government.

In an attempt to pressure to Government to act, Independent Western Australian MP Kate Chaney plans to introduce a private member’s bill seeking to exempt VAD from the Criminal Code early this year.

We will continue our lobbying on this vital issue and keep you informed of developments.

