

From the President

We have spent a lot of time with our DWDWA counterparts considering a response to the respective reviews of the operation of the VAD legislation.

The Victorian Act says that "The Minister must cause a review of the operation of this Act to be conducted, and that the review must be conducted in the fifth year of the operation of the Act and be a review of the first 4 years of operation of the Act." This would see the review start no sooner than 19 June this year, but we see no evidence of any enthusiasm from the government for the task at hand.

Despite asking for guidance on what terms of reference there might be, we have had nothing of any informative value from the Victorian Department of Health.

We have therefore made preparations for a submission to the review with the assumption that the terms of reference will be broad.

We have been grateful for the work done by DWDWA in assisting us in this exercise. The minimum we might hope for should include consideration of consistency with other Australian Acts.

However, we have also given consideration to a widening of the eligibility criteria. The results from the survey we conducted (see article on page 2) indicated concern over many aspects of the operation of the Act, and the Act itself.

In this regard, assistance from The Age journalist Michael Bachelard has been helpful in documenting the wide-spread wish for mental conditions, specifically dementia, to be a criterion for VAD.

Whilst our own survey might be indicative, it must be noted that our survey was directed to those who have had some exposure to the VAD services.

We are investigating the feasibility of a broader based survey, seeking public interest in the topic of Dementia in the context of VAD.

The Carriage Service issue has not been resolved – it is still assumed that use of Telehealth is not permitted in relation to VAD.

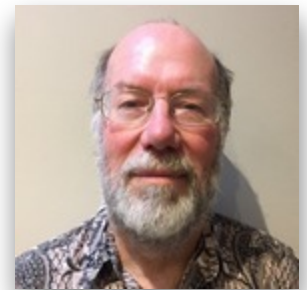
Our Dr Carr may have to front Federal Court to seek 'judicial interpretation' on the meaning of terms in the Criminal Code Act 1995, as the Attorneys General of Australia seem to have more important things to do than ease the way for people suffering intolerably from certain terminal ailments.

The apparent ban on doctors even using the telephone in carrying out their work places an unacceptable burden on them and their patients.

Another impediment to the provision of VAD concerns the absence of Medicare support.

We have sought a change to have the last stage of VAD covered under Medicare. To that end we have provided the relevant Commonwealth body with the means to provide for this, but have received an unhelpful response.

We will seek other means to have this problem fixed.



Hugh Sarjeant



DWDV survey of attitudes to voluntary assisted dying

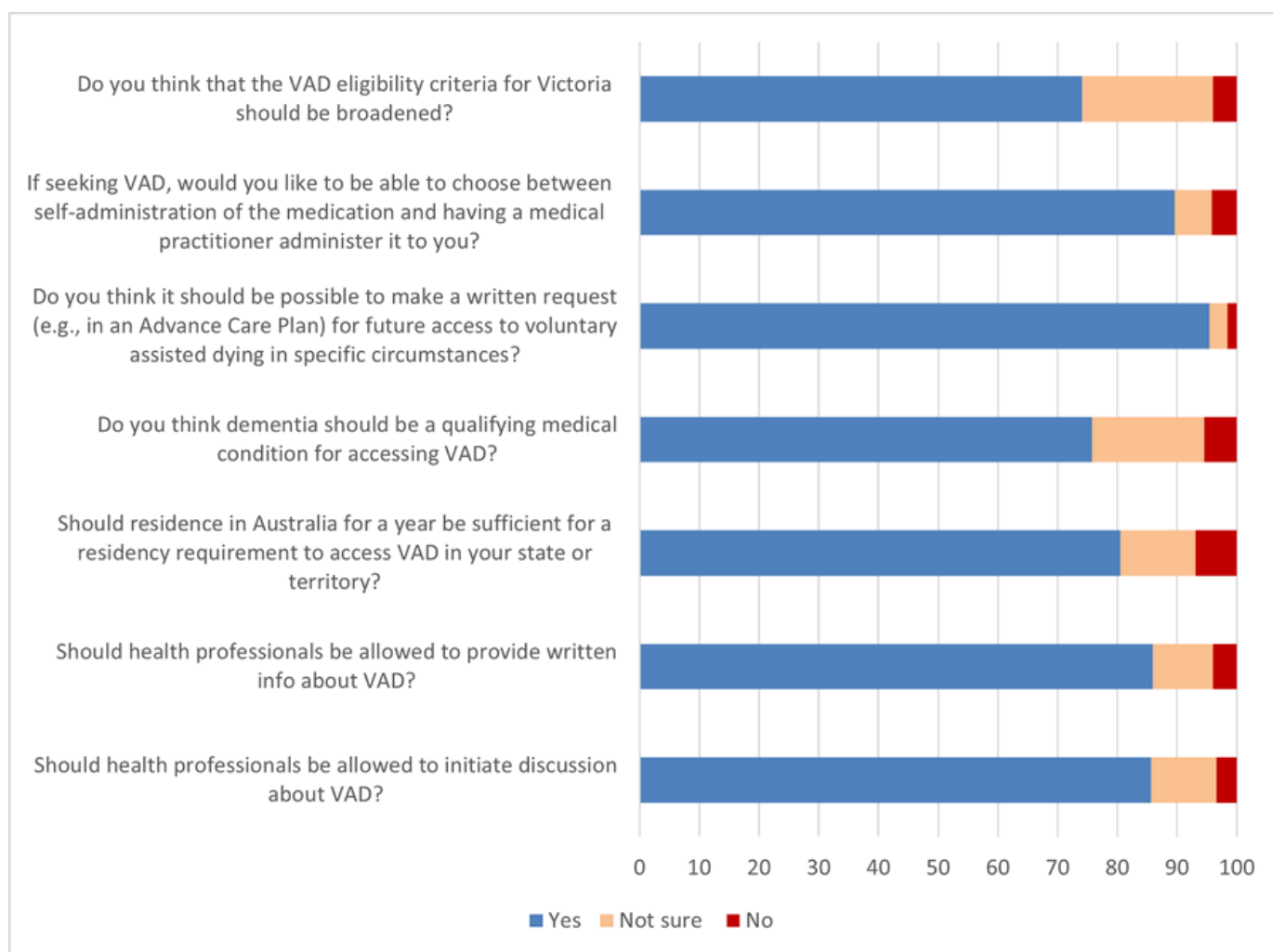
In late 2022, Dying With Dignity Victoria (DWDV) invited contacts via email, its website and social media to complete a survey of their experience with – or understanding of – voluntary assisted dying.

Interestingly, of the received 677 responses, 72% were from people identifying as female. 41% of all respondents had had some involvement with the VAD process, most of which (89%) had been in Victoria.

Of the respondents, 16% were professionally involved in the VAD process, while some 21% were involved with a friend/loved one accessing VAD.

62% of respondents were aware of some problems with the VAD process.

The following chart shows the ways in which most respondents would like to see the current provisions of the law changed. Very few would oppose any of the canvassed possible changes.

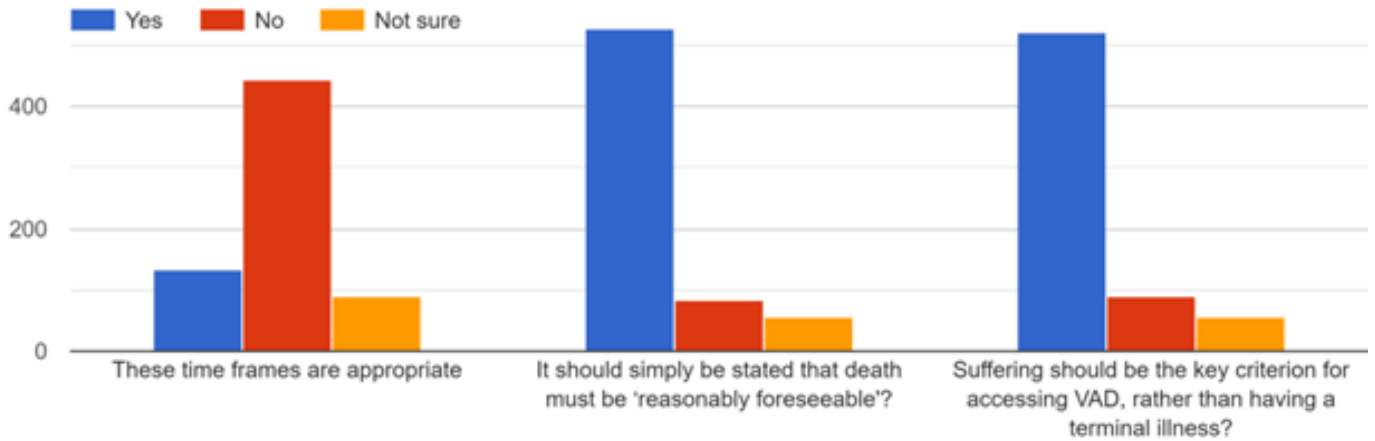


Email: dwdv@dwdv.org.au
Phone: 0491 718 632
Address: PO Box 743, Kew, VIC, 3101,

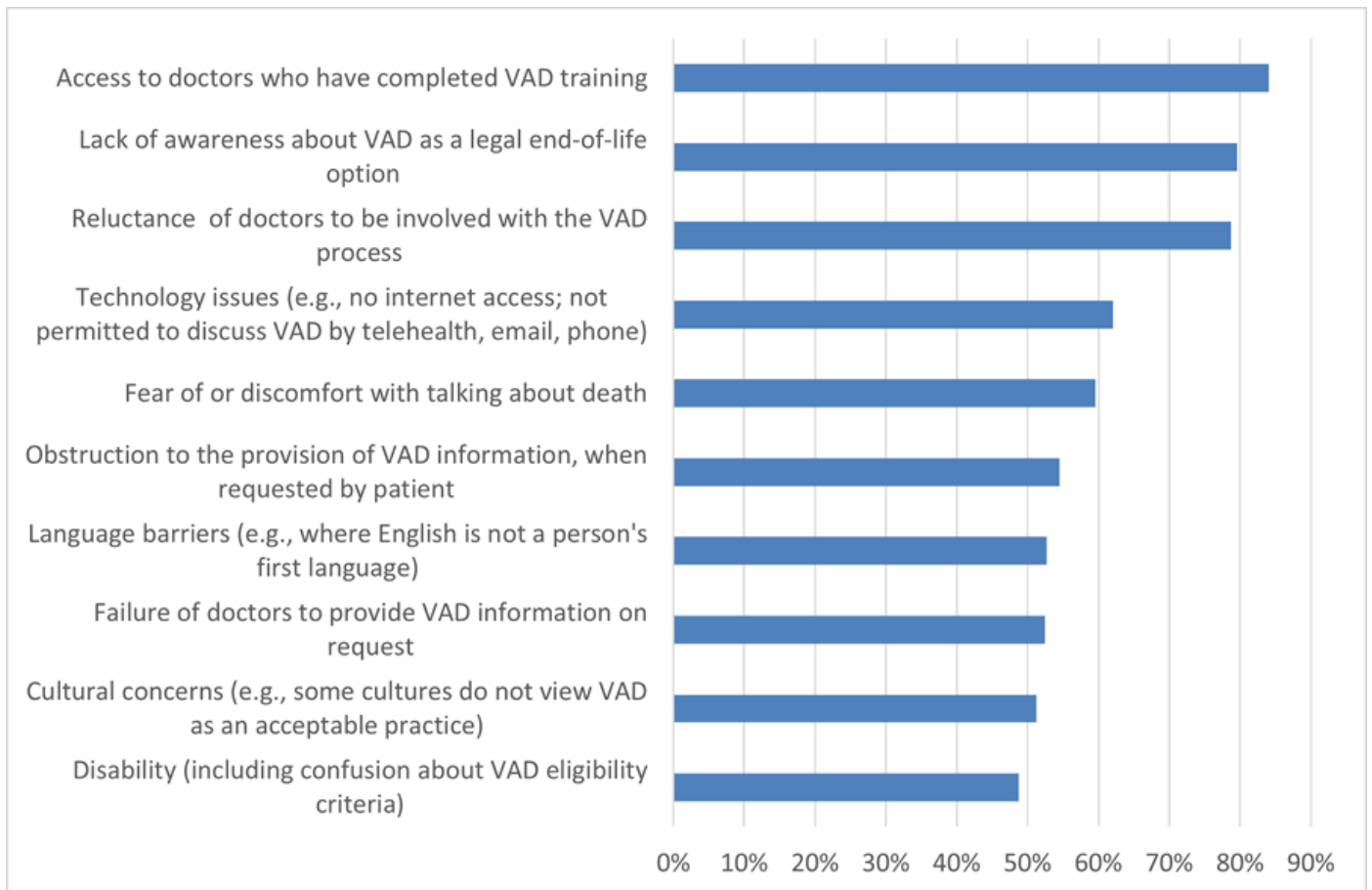
Of the 435 who considered the criteria should be broadened, 114 (26%) mentioned dementia.

The Victorian VAD Act requires that death must be expected to occur within 6 months or, in the case of neurodegenerative illness, within 12 months. Survey respondents were largely of the view that:

- These times are NOT appropriate, and
- It should simply be stated that death must be 'reasonably foreseeable', or
- Suffering should be the key criterion for accessing VAD, rather than having a terminal illness.



Many respondents consistently identified a number of problem issues.



New Board Member - Danielle Clarke



DWDV is thrilled to announce that as well as becoming a DWDV Young Ambassador, Danielle Clarke has joined the Board of DWDV. We are all looking forward to working with her.

I am a public health professional with a passion for patient-centred care. VAD policy became a particular interest of mine during my Masters studies of Health Policy at University. I have previously studied Biomedical Science and ethics at University and have a fellowship from the Institute of Community Directors Australia.

I am honoured to be a part of this important organisation and to work alongside such dedicated individuals. Together, we will continue to raise awareness and fight for the rights of all individuals to make informed and autonomous decisions about their own care.

Posthumous OAM awarded to Nia Sims

Congratulations to the late Nia Sims OAM. Her selfless courage and incessant compassion shown towards others has been deservedly rewarded with a Medal of Order of Australia.

A very special individual loved and admired by all, never forgotten and greatly missed.

Nia died in 2022 through VAD, and was honoured on the King's Birthday holiday with an OAM for her service to community health.



Personal stories

Joy tells a moving story about her brother's death; how incredibly difficult the final weeks were as his brain tumour changed his personality, and also about the wonderful support he and the family received from Dr Cameron McLaren and the VAD team.

She has also shared a letter she wrote to "My Dear Fellow Advocates" - about a role that can be "incredibly comforting but also so very rewarding".

Sally shares her story as she faces her final days and will soon receive her VAD medication. She does this to help others, even though she won't be able to benefit from future changes in legislation to make access to VAD easier.

Read these stories - and more - on our website under *Personal Stories* in the top menu.



DWDV Presentations for Groups

Now that Covid restrictions have been lifted, there has been a growing interest for DWDV to speak to organizations such as Probus and U3A around Melbourne.

By request, DWDV offers on-site presentations to organisations, on aspects of end-of-life choices such as Advance Care Planning and Voluntary Assisted Dying. There is always time allowed to respond to questions at the end of each presentation.

DWDV has noticed that, increasingly, many questions relate to VAD and Dementia (disallowed in our current legislation) but this is an issue of great interest to many of the groups we have presented to.

We direct audiences to our DWDV website where they can read more about Advance Care Planning and appointing a Medical Treatment Decision Maker.

The forms required, as well as information on how to complete them can be downloaded from the DWDV website.

We encourage our audiences to discuss their end of life plans with their loved ones and, of course with their treating medical professionals.

Requests for speakers can be made through a form on our website under *Our Services > Request a Speaker*. There is no charge for this service.



Jane Morris, DWDV Vice President, presenting at Probus

VAD Supportive Funeral Providers

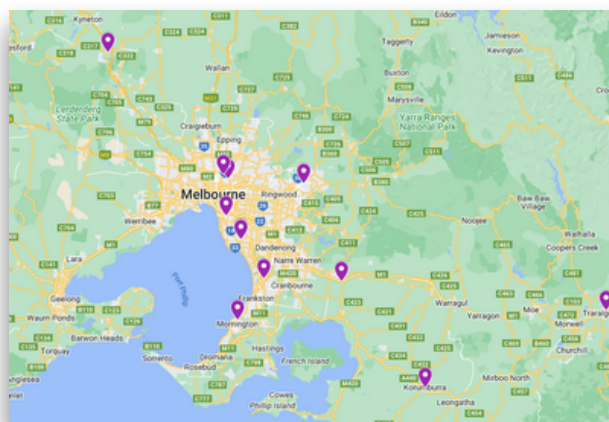
We are compiling a list of funeral providers supportive of Voluntary Assisted Dying.

You will find this on our website under the *Our Services* menu item.

There is a button you can click to open a Google map showing the location of providers who have responded to us indicating they do support VAD.

We will continue to work on providing a comprehensive listing, which will be updated regularly.

If you're aware of any other funeral providers you believe would be willing to be added to the list of those supporting VAD, please contact us to let us know.



Asian Medical Students Exchange Program (AMSEP) and VAD



Dr Nick Carr

On a blustery Melbourne Sunday in June I locked my bike outside the East Melbourne library, only to find the library itself locked and silent. Hmm. I was due to give a talk, but there were still 15 minutes before the start time. Sure enough, in response to some enthusiastic knocking (and a phone call or 2), the doors magically opened.

“Sorry, they’re on a break, so we sent them to have a wander around East Melbourne. They’ll be back soon.”

‘They’ were 27 visiting medical students, here for AMSEP’s week of activities. Last year it was students from Taiwan who’d had to listen to me discussing VAD, this year it was the turn of Thailand.

The students were evenly divided between 1st, 2nd and 3rd years and, despite it being a Sunday, seemed eager to get involved. I did note however that several wore masks throughout, a technique I have occasionally employed myself during consultations to hide the odd yawn, but I’ll stick with eager.

I started with my usual advice that the content could be confronting and if too much so, anyone was free to leave. As last year, no one chose to go. I hope this was not just out of politeness.

I then asked them to say whether they felt supportive about VAD, opposition to VAD or unsure. The split was around 2/3 supportive to 1/3 unsure, with no one brave enough to express opposition.

I told them the story of the extraordinary Beverley Broadbent and how she’d ended her life, not because she had a terminal illness, but because her life was complete and she wasn’t prepared to risk declining to a state where she couldn’t exercise her own choice.

That when I had asked how she knew when was the right time, she answered, “You know how my friends and I love the theatre? Well, I saw that there was a new show on in Sydney, which I really wanted to see. Then I thought, no, I’ve seen enough shows. That’s how I knew.”

They tolerated my meander through the history and process of VAD and then, to my delight, launched into a barrage of questions.

I was hugely impressed by their sophistication and understanding of some of the complexities of VAD, with questions about (in no particular order, my memory isn’t that good):

- Why isn’t palliative care enough?
- What level of support for VAD is there in the community? What about amongst doctors?
- Questions about the experience for family members.
- Questions about the medications used.
- Why would anyone get involved in this work?
- Why can people go to Switzerland for VAD when they’re not eligible here?
- What about dementia, or people who do not have a terminal illness but who’ve ‘had enough’?

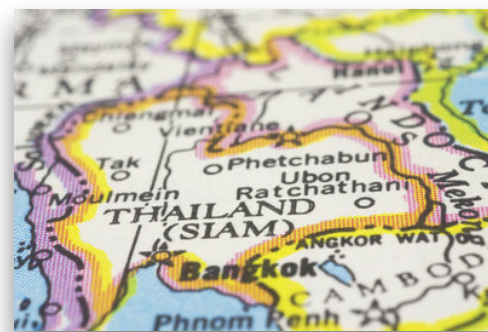
We talked about the concept of the completed life and why that should (in my view) be an acceptable reason for VAD.

One student asked, “What if a 37-year-old said she’d completed her life, that she’d seen enough shows; VAD please?” Such a great, intelligent question, and led to a discussion about the role of mental illness, but also that there are often no clear answers.

If these young students are any example, the future of medicine in Thailand is in good hands.

The hour whizzed by, then it was time for their lunch. I was thanked and given a rather lovely keep-cup.

Hopefully they’ll ask me back next year.



Rodney's Book

Following the death of Dr Rodney Syme, it came to our attention that Rodney had almost completed the draft of a book, 'A Completed Life'.

In this book he described Dementia as "the worst journey in the world."

He asked, "If a person's journey is complete, why do we determine that they must go all the way to the terminus - why can they not elect to get off one or two stops before the end?"

Rodney urges society not to turn a blind eye to those suffering at the end-of-life. These people desperately need to be provided with a voice and acknowledgement.

His book focuses on the plight of those with dementia and as indicated by the title of the book, looks at those who have led a long life, have achieved all that was possible and are now comfortable in accepting that they have completed their lives.

They are ready to die as life for them no longer provides pleasure or purpose. They no longer feel useful and mourn their lost independence. They have lived their final chapter and are now ready to close their own book.

Rodney draws from his knowledge and experience as one of the world's authorities on end-of-life needs. Tragically he also wrote from personal experience.

As he wrote, he watched his beloved wife, Meg, slowly succumb to Alzheimer's disease. For the last 3 years of Meg's life Rodney took on the role of her devoted full-time carer. It was during this time that he became fully aware of the "sadness, cruelty, and terror" associated with dementia.

Several articles in "The Age" have recently probed what many people consider to be the critical issue of individuals with dementia being denied access to VAD. The response to these articles was enormous.

DWDV received many stories from people who had witnessed a loved one suffer horrifically from a dementia related death. Those who had lived with a family member with dementia referred to the intense fear they now have of receiving a dementia diagnosis themselves and their fervent desire to be able to access an assisted death.

We wish to honour Rodney's legacy by ensuring that this last message is heard, and we are therefore intending to publish "A Completed Life".

We hope to have the book "on the shelves" in a few months time.



VAD and Dementia in the News

It is encouraging to see that the issue of access to VAD for dementia patients is gaining attention in news media.

In a recent news post on our website we highlight three articles from The Age newspaper on this issue including the one written by Senior Editor Michael Bachelard.

Read more here: <https://www.dwdv.org.au/news/>

NEWS FROM AUSTRALIA ...



Australian states that have passed VAD legislation have seen that they must remain vigilant as those opposed to the legislation are ready to spring into action. In April, the Standing Council of Attorneys-General met and it was anticipated and hoped that the problem resulting from the Federal ban on VAD electronic carriage service consultations would be resolved. Prior to the meeting the VAD opposition came out in full force. The Australian Christian lobby released a petition for members to sign that opposed the removal of the ban. The Right to Life devoted 8 pages of their 12-page newsletter vehemently opposing any move to overturn the ban. Leaflets were also distributed in the Federal electorate of Aston, prior to the by-election. Recipients of the leaflet were informed that a Labor Government would overturn the ban on the prohibition of VAD telehealth consultations which would mean that an individual could be provided with a VAD permit simply by conversing with a doctor over the phone or other carriage service.

Queensland

In April, State MP, Aaron Harper, who chaired the Queensland Parliament Health Committee and was integral to achieving VAD legislation in Queensland, shared his serious concern about the results of the forthcoming 2024 State election. He expressed a strong view that the LNP, who lean to the far right and are dominated by the Catholic Church, will not give people choice on progressive and important issues affecting their lives. He is deeply worried that should the LNP be voted in, there is the possibility that VAD and Termination of Pregnancy Laws could be repealed.



South Australia

In April the Minister for Health and Wellbeing announced that the existing 8-member Voluntary Assisted Dying Review Board would be increased to allow for the appointment of a representative of the Aboriginal and Torres Strait Islander communities. South Australian Health released the first quarterly report into VAD. This covered the first 3 months of operation from 31 January to 30 April 2023. It stated that 28 VAD permits had been issued and from these 12 people had accessed an assisted death. One hundred and five doctors had registered to do the VAD training of which 60 had completed the training.



Victoria

One of the most frequently asked questions relating to Voluntary Assisted Dying is why individuals with dementia are unable to access an assisted death. It has been the elephant in the room for a long time but in May it was courageously addressed by The Age journalist, Michael Bachelard. His article "Dementia sufferers deserve dignified death" resulted in an avalanche of responses and has certainly put this critical issue out there for public discussion. Bachelard's article was followed up by an opinion piece by a Victorian geriatrician who argued that people with dementia should have access to VAD. Dementia Australia issued a position paper on VAD and stated that people with dementia should have the same rights as other Australians to exercise choice about their end-of-life journey, and this might include equal access to VAD.



NEWS FROM AUSTRALIA (cont) ...

The ACT

There has been quite a bit of news emanating from the ACT. In April, former NT Chief Minister Marshall Perron stated in an interview (addressing future ACT VAD legislation) that he urged the ACT to allow individuals under the age of 18, suffering from a non-terminal illness/incurable illness the option of accessing VAD. He also suggested that life expectancy prognostication be dropped and that individuals diagnosed with dementia should be provided with the option of requesting an assisted death in an Advance Care Directive. In May it was announced that the ACT government will launch a compulsory acquisition process to take control and ownership of Calvary Public Hospital Bruce. There has been a strong backlash from the Catholic Church with the organization of rallies, petitions and even the prospect of a legal challenge being raised. The issue of government funded hospitals refusing abortion and VAD is a very critical one.



New South Wales

In its May update, Dying with Dignity New South Wales reported on the excellent progress being made by the NSW Health Department in preparing for VAD to become available on November 28 this year. The NSW Health Implementation Team have held many successful webinars and are working alongside a range of groups.



... AND AROUND THE WORLD

Belgium

The Belgium euthanasia regulatory body published its 2022 report. The report showed that there had been an increase of over 9% in the number of euthanasia deaths in 2022. Most people were aged in their seventies and eighties.



Canada

Numerous stories continue to come out of Canada. The expansion of access to MAiD for those diagnosed with mental illness as the sole underlying disorder, was earlier this year delayed until March 2024. This has resulted in heart rending stories of those waiting to access MAiD being forced to endure another agonizing 12 months. It was reported that 9 Canadian prison inmates had sought an assisted death since the implementation of MAiD in 2016. Another extremely contentious issue has been the 'reported' provision of MAiD to those suffering extreme poverty, dire social circumstances and those suffering from disabilities who are unable to access adequate support. Recently a funeral home in Quebec allowed the process of MAiD to occur on its premises. Immediately opponents of MAiD queried the legality of this event and asked whether it commercialized the procedure of death. However, there are many incidents of people seeking an assisted death being evicted from faith-based health facilities and having nowhere to go. Many people do not want to die at home and there is a growing demand for places for them to go. In recent news from Quebec Bill11 has been adopted. This Bill will allow people with degenerative illnesses, such as Alzheimer's disease, to make, upon diagnosis, a request for an assisted death in an Advance Care Request.

AROUND THE WORLD (cont)

Cyprus

The trial of a British pensioner continues. The man is on trial for the 2021 murder of his wife, in Cyprus. He states that she repeatedly begged him to end her life because of the extreme pain she suffered from terminal cancer. He could face life in prison if convicted.



Denmark

It has been reported that a petition to legalize VAD in Denmark has gathered 50,000 signatures. This is the number required to compel debate on the subject in parliament.

France

In early April President Macron promised to introduce an end-of-life bill by the end of the northern summer. He did not specify whether this would include the topic of assisted dying. A citizens' convention on end-of-life issues released its findings after a four month discussion. It spoke favourably about allowing active assistance in dying. The French Health Minister has however expressed reservations about the findings and suggested that improvements in Palliative Care would be preferable.

Ireland

The much-awaited Special Oireachtas Committee on Assisted Dying finally met in April for its first meeting. The committee is now examining how assisted dying might operate in Ireland. A special information campaign is being currently conducted and is organized by Irish doctors who are supportive of assisted dying legislation and the advocacy group End of Life Ireland. The head of Exit Ireland reported a ten-fold increase in inquiries.

Italy

A great commotion resulted from news that the President of the Pontifical Academy for Life had spoken out, during a recent television panel debate on assisted dying. He had stated, "Personally, I would not practice suicide assistance," he said, "but I understand that legal mediation may be the greatest common good concretely possible under the conditions we find ourselves in." The next day his office issued a statement saying that his remarks had been incorrectly interpreted and the following day he was said to have reaffirmed his opposition to "euthanasia and assisted suicide".

Japan

A controversial film recently released in Japan has received global attention. The film "When 75 is time to die" addresses the issue of Japan's rapidly ageing population associated with high life expectancy. The Prime Minister had announced that the ageing population posed an "urgent risk to society". This film, although fictitious, provides a solution to the problem. It suggests that those who reach the age of 75 be considered eligible for 'euthanasia'.

New Zealand

The Ministry of Health released the Assisted Dying Service report that covered the period of November 7, 2021 to November 6, 2022. It noted that 661 formal applications for assisted dying were received and that 257 people had accessed an assisted death. Interestingly, 82% of those died at home.

Norway

Results from research conducted by the University of Oslo have found that around two thirds of Norwegians are in favour or 'somewhat favour' assisted dying, for those with a terminal illness, in which medication is either self or physician administered.

Portugal

After 4 attempts to have an assisted dying bill legalized in Portugal, a bill has been finally passed and more importantly, unlike on similar occasions in the past, the bill was not vetoed by the Portuguese President. Opponents of the bill have not ruled out the possibility that the operation of the act could be hampered.

AROUND THE WORLD (cont)



South Africa

A professor of ethics and VAD campaigner announced that he is ready to mount a case before the courts that denying people the right to an assisted death is against the constitution.

Taiwan

An opinion piece by a law professor argued that Taiwan should legalise VAD, if only to prevent terminally ill people taking their own lives.

The Netherlands

The Dutch Euthanasia Review Committee published its 2022 report. It reported that in 2022 8,720 people accessed an assisted death. This was an increase of nearly 14% from the previous year. It was reported that there was an increase of 34% in individuals with dementia requesting an assisted death. There were also 379 couples who achieved an assisted death, an increase of 23% from 2021. The Netherlands will broaden its 'euthanasia' rules to include terminally ill children aged between 1 and 12 years of age. It is expected that between 5 and 10 children a year, who suffer unbearably, where there is no likelihood of improvement and for whom palliative care cannot bring relief, will be considered for eligibility. In 2022, there was only one report of a child, aged between 12 and 16, accessing an assisted death.

United Kingdom

The UK Health and Social Care Committee's Inquiry on Assisted Dying is currently being conducted. The House of Commons Select Committee finished examining submissions and hearings have commenced. Experts from jurisdictions around the world that have successfully campaigned for and now implemented VAD have spoken. There was welcomed news when long-time advocate for VAD, former Archbishop of Canterbury, Lord Carey, renewed his call to MPs to allow time for the debate of a VAD law. Meanwhile The Royal College of Physicians have allegedly adopted a so-called VAD "neutral position". UK bishops have spoken out against the adoption of assisted dying citing the Canadian MAID situation as a warning to others.

Scotland

The *Assisted Dying for Terminally Ill Adults Bill* is currently being drafted and is expected to be presented to Parliament later this year. The Church of Scotland has said that they will re-examine their opposition to Assisted Dying.

Isle of Man

Views on assisted dying are said to be poised on a knife edge. An MP has stated that he intends to introduce an assisted dying bill this year.

Jersey

It is expected that Jersey will legalise assisted dying by 2023. Proposals from a public consultation, to be considered by the States Assembly, will take place next year after it was decided further information was required from specialists with a background in medical ethics and the law. If approved a bill will be drafted in March 2024.

United States

The **Nevada** End of Life Options Act passed its final vote out of the Assembly. The bill now returns to the Senate for concurrence and then to the Governor's desk. This is the furthest stage an assisted dying bill has ever reached in Nevada. The **Hawai'ian** Governor has signed Bill HB650 that will expand access to MAID for terminally ill Hawai'ians. In **Delaware** a VAD bill has been passed through a committee stage and is standing ready for debate in the Delaware House of Representatives.

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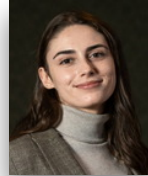
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We are deeply appreciative of the amazing work done by all our volunteers, but we also rely on the generosity of donors and other benefactors to help us support the right to individual end-of-life choices through voluntary assisted dying, advocate for improvements to current laws and provide support and education for individuals, organisations and communities.



Would you consider making a donation to DWDV?

You can do so through our secure online form here: <https://www.dwdv.org.au/donation/>
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Alternatively, contact our office for details to make a payment by direct bank transfer or cheque.

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