

President's Update

The recent intense media focus on the terrible death of a man living in regional Victoria has highlighted the dire need for the federal ban on VAD Telehealth consultations to be addressed as soon as possible.

We believe this topic was brought up at the meeting of the Federal and State Attorneys General on 9 December, but no details were provided. It is still hoped that the Act will come before Parliament in the new year and will be resolved. Options include amending the Crimes Act, perhaps by stating that for the purposes of the legislation Voluntary Assisted Dying is not considered suicide. Alternatively, we have heard a rumour that they might just state they will not prosecute in such cases. A rather weak alternative, but it would suffice for now.

Meanwhile, DWDV Board member Dr Nick Carr is seeking a judicial interpretation of the law from the Federal Attorney General, and has a date set in the Federal Court in the second half of May. This had been listed for early November but the Federal Attorney General Mark Dreyfus was granted an adjournment for the case, presumably to enable the AGs of Australia to come up with a plan that would remove the need for taking the matter to court.

For our own activities, the major task at present is to prepare for the 5-year Review. The information provided by the Victorian VAD Act is sparse:

"116 Five year review

- (1) The Minister must cause a review of the operation of this Act to be conducted.*
- (2) 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.*
- (3) On completing the review, the Minister must cause a report of the review to be tabled before each House of the Parliament."*

It seems the Review process will commence around June next year, and the community will be offered the opportunity to express opinions, and so shall we. Coincidentally the Western Australian Act states that WA will also conduct a review at about the same time. This will assist in the exchange of ideas and, hopefully, a move toward legislation that is consistent across Australia.



Hugh Sarjeant

Our survey on issues of concern for the review has provided some interesting results so far. If you have not already done so, please add your contribution to the survey:

<https://www.dwdv.org.au/dwdv-vad-survey/>

Also, there is an important matter to consider in relation to a Medicare problem. No rebate is available to doctors providing service to the person at the time they are to take the medication. In addition, there is not a Medicare item number allocated to home visits by a Specialist. This is an extra expense incurred by doctors, and the matter is not trivial. It has taken as long as seven hours in one such case to provide the support sought. We have asked for advice on how best to proceed.

Our plan to publish Rodney Syme's work "Completed Life" is on hold. We are hoping to add some contributing essays from individuals who were involved with the subject content. We have been advised that the inclusion of these essays will complement Rodney's material and allow the authors to respond to any media inquiries.

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Despite some minor hiccups with technology, our AGM was held on November 12 and ran successfully. We were pleased to have VAD Review Board member, Dr Jim Howe, as guest speaker. Professors Ben White and Lindy Willmott of QUT were awarded Rodney Syme medals in recognition of the huge contribution they have made to end-of-life law in Australia and for the support they provide to us.

From a VAD perspective, it is a relief that the ALP have been successfully returned in the recent Victorian election. Prior to the election it was thought that some Coalition members intended to amend the VAD legislation and make it unworkable, were they to win the election. Other Coalition members indicated they would not seek to repeal the VAD legislation, and some even indicated support for the Act. Our two allies, Fiona Patten and Stuart Grimley, have sadly lost their positions in the upper house in the election. Both have actively supported us, and we are very grateful to them.



Our two-monthly meetings with the other DWDs of Australia continue to provide a helpful forum in which to discuss matters of mutual interest. We are now also joined by reps from New Zealand, and Christians Supporting Choice for Voluntary Assisted Dying. Further, we now have a Young Ambassadors group and there are plans for next year to implement the next stage of the SAV group - Support After VAD. These 2 topics are discussed in more detail in this newsletter.

I wish all our members and supporters a happy festive season and a happy and healthy 2023.

SAV – Support After VAD

DWDV has been busy creating care connections in our community with the establishment of our Support After VAD group, SAV. We have established a core group of volunteers across Victoria. We are extremely grateful to Nicole Grundy for leading the group.

While the program is still evolving, we believe we have been able so far to provide a gentle place to land for Victorians who have supported a loved one through the Voluntary Assisted Dying Process. With the selfless help of many kind-hearted individuals volunteering to tell their story, and the willingness to listen compassionately to the stories of others, we have created a safe place for people looking to connect with a peer who has also traversed the VAD journey.

This year we have fine-tuned the intake process, created a benchmark, looked at response times and a formed a process for the pathways in which we can introduce others.

This is not a counselling service or professional support for individuals grieving a VAD loss. It does not offer peer support to individuals going through the VAD experience. At this stage, we offer only one-on-one peer support to those who have accompanied a loved one through the VAD process.

We will continue to build DWDV support resources as the needs in our community grow and awareness rises. We acknowledge that it takes time to build trust and we feel we have achieved this over the last 12 months by establishing a place of compassion; a place where individuals can connect.

Our goal in 2023 is to continue creating a network of individuals and build meaningful connections of support and community care through all stages of the Voluntary Assisted Dying process.

We would like to sincerely thank our wonderful volunteers. Their desire to willingly help others is admirable and so greatly appreciated.

If you would like to speak to one of our volunteers or become a volunteer yourself, please contact the DWDV office.



Niccole Grundy

WFRtDS Conference – Toronto

BY JANE MORRIS

It was a great privilege to attend the World Federation Right to Die Societies biennial Conference 2022, in Toronto. I had the most fantastic time and met some amazing individuals.

It was fascinating to hear the progress that has been made, or in some cases lack of progress, around the world by organizations, all of whom have a common purpose to provide humane and compassionate end-of-life choices for their societies.

Anne Bunning, VADSA and Secretary of the WFRtDS, Palliative Care Physician Dr Greg Mewett, Ballarat and Mike Gaffney MLC, Tasmania were also there and ensured that a fun time was had by all!

Anne Bunning and I have compiled a summary of events and presentations from the Conference.

On our websites, DWDV and VADSA, we will be adding some photos and brief videos of a few Conference attendees commenting about end-of-life issues in their respective countries.

Read more, see the photos and listen to the videos on our website under:

Resources > WFRtDS Conference – Toronto 2022



President of WFRtDS, Asunción Alvarez, presenting the 'Marilynne Seguin' award, accepted by Jane Morris, on behalf of Shayne Higson

Shayne Higson receives 2022 Marilynne Seguin Award

Shayne Higson, CEO DWDNSW, was chosen by the World Federation Right to Die Societies as the recipient of the 2022 'Marilynne Seguin' award. This award is given "For the person who has achieved much in her/his country for their national right-to-die movement".

Following the torturous death of her mother from brain cancer in 2012, Shayne has dedicated her life to Voluntary Assisted Dying advocacy.

She was instrumental in the establishment of the Voluntary Euthanasia Party and ran as a lead VEP candidate in both Federal and State elections. She was not elected, but her foray into politics drew a lot of attention to the critical need for a legal, compassionate end-of-life choice.

She generously provided her time, knowledge and experience in media, graphic design and social media with the other Australian DWD organizations.

As a spokesperson Shayne is always respectful and courteous to those whom she interviewed and, as a result, deservedly earned the respect and admiration of so many.

We cannot think of an individual more worthy of this award. Shayne's work and her warm personality that displays genuine care and concern for others is admired by all.



Shayne Higson

After the Fall



Dr Nick Carr

When we were kids, we used to engage in all sorts of gruesome thought experiments. Would you rather go deaf or blind? Which would you choose, being eaten by a shark, or being boiled alive? Lose a leg or lose an arm? A variation – if you were paralysed from the waist down, would you choose to live? What about if it were from the neck down?

I don't remember the answers to the other questions, but to that last one the response from us kids was universally nah, bullet in the head rather than live on, thanks. And I know many adults today who would say the same thing. Quadriplegia - no quality of life, totally dependent on others, no point in going on. "You wouldn't let your dog live like that". I'll take the bullet.

Being a medico brings you into contact with the best and worst that can happen to people. It brought me into contact with John. Young, handsome, ambitious – until he fell down some stairs, broke his neck. Not dead, not paraplegic, but quadriplegic. Months in the spinal unit, then home to his lovely wife, for her to begin her career as a full-time carer. They were both in their twenties.

For several years I visited him at home as his GP, until he was able to move one hand enough to operate an electric wheelchair. Accompanied by a carer, he could finally make his way to the surgery. Ten years after his fall he came in, and I asked, "How are you going?", and his answer was, "Couldn't be better". I looked at him and I thought, you need someone to feed you, someone to move you in and out of a chair or bed, someone to dress and undress you, someone else has to do pretty much everything for you, even help empty your bowels; yet this was your honest answer. Couldn't be better. And his smile told me that he meant it.

I've known John now for over 30 years, and life is still good.

One criterion under the VAD Act is that the person is experiencing 'intolerable suffering'. It doesn't matter what anyone else thinks, it's the person's own experience that matters. Suffering is intensely personal; what is unbearable to one might be manageable for another. But it can also change, the condition that in our thought experiment we believed would be intolerable can turn out not to be so.

Never underestimate the human spirit. You taught me that – thanks, John.

Forest Therapy

Inspired by the Japanese Public Health Practice 'Shinrin-yoku' (also known as 'Forest Bathing'), Forest Therapy is an evidence-based approach where the restorative power of nature is harnessed to heal many ailments of modern life. Along with stabilising and improving mood and cognition, research shows that Forest Therapy can improve sleep quality and boost the immune and cardiovascular systems.

We have an article by Emma Swann (from It's Naturally You) on our website, discussing the benefits of Forest Therapy for the terminally ill. We also provide links to three businesses offering this service and share how Forest Therapy provided great comfort and peace for the late Nia Sims, an extraordinary and selfless Voluntary Assisted Dying advocate.

You'll find this on our website under Other Services > Forest Therapy.



2022 Rodney Syme Award

DWDV was thrilled to announce that the 2022 Rodney Syme medal was awarded to the amazing Ben White and Lindy Willmott, Professors of Law at the Australian Centre for Health Law Research, QUT (Queensland University of Technology).

They have been highly influential in the VAD law reform processes throughout Australia.

Congratulations Lindy and Ben. A greatly deserved award.



Dr. McLaren speaks at World Cancer Congress

Dr Cam McLaren, Oncologist & DWDV Board member, has just returned from the World Cancer Congress in Geneva where he participated in a debate "All cancer patients should have medical access to dying in all countries".

His opponent was Professor Baroness Ilora Finlay, a palliative care specialist and member of the House of Lords. Cam spoke from the heart and his compassion and empathy for those suffering at the end of life was evident throughout the entire debate. Cam's respectful and composed delivery of his VAD knowledge and experience with cancer patients at the end of their lives was reflected in the results taken at the end of the debate in a poll.



DWDV is so proud of Cam, as all Australians should be. You can listen to his presentation on our website here:

<https://www.dwdv.org.au/dr-mclaren-speaks-at-world-cancer-congress/>

Personal Stories

We've added some new *Personal Stories* on our website. Bev's aggressive cancer allowed no time for her to apply for VAD, leaving her daughter with several unanswered questions. And *VAD Eligibility Guilt* looks at how some people can experience a sense of guilt arising from the fact they have been considered eligible for VAD, whilst others who suffer similar illnesses and comparable suffering are considered ineligible.



Email: dwdv@dwdv.org.au

Phone: 0491 718 632

Address: PO Box 743, Kew, VIC, 3101,

Meet the DWDV Young Ambassador team

Dying With Dignity Victoria would like to welcome its inaugural Young Ambassadors, who come from complementary backgrounds that will see a successful program promoting DWDV to young people.

Olivia ('Liv') Nicholls, Jono Simko and Anna Philip are very excited to be a part of the DWDV team.

OLIVIA ('LIV') NICHOLLS

Liv was a policy adviser to a Member of the Victorian Parliament for four years including developing Voluntary Assisted Dying policy. Liv developed an interest in the issue and eventually developed a Private Members' Bill which was introduced to Parliament in 2021. The Bill sought to address the 'telehealth' issue and the 'permanent residency definition' issue within the current Act.

Through this advocacy work, she has met many people affected by the lack of end-of-life options, as well as accredited GPs and VAD advocates. She believes in having the choice to die with dignity and that whilst checks and balances must be in place, that the current scheme needs improvement. Liv is proud to be an advocate for DWDV, and admires the incredible work we do to instill rights, power and dignity back to terminally ill people who have been denied their autonomy for too long.

She has also witnessed the slow and devastating deaths of family friends who may have chosen VAD if the option was more readily available.

Liv hopes that the DWDV Young Ambassadors can contribute to the 5-year review of the VAD scheme in Victoria.



JONO SIMKO

Jono is a young professional living in Melbourne, who currently works in the software industry in a strategic marketing role. He is passionate about the opportunity to be a Dying With Dignity Young Ambassador and believes the topic of assisted dying needs more awareness amongst the younger demographic of Australia. This includes education for individuals, and their relations who may benefit from an Advance Care Plan.

Within the last few years, Jono has lost both his mother and uncle to neurodegenerative diseases and wants to share his own experiences on end-of-life to encourage a positive conversation that normalises the concept of death to younger people.

He is keen to use his professional experience to help guide the strategy and implementation of initiatives for DWDV in 2023.



A WORLD OF CHAMPIONS

For World Right to Die Day 2022, The World Federation of Right to Die Societies highlighted a World of Champions, *"telling the stories of the parents, siblings, activists, doctors, supporters and volunteers who are working to make dying with dignity possible from all the corners of the earth. It is a testimony of their struggle and the complexities they face in championing the right to die with dignity."*

They created an interactive pdf map of these stories, which you can download from our website here: <https://www.dwdv.org.au/world-right-to-die-day-2022-world-of-champions/>

ANNA PHILIP

Anna is a physiotherapist working at Peter MacCallum Cancer Centre, where she has been exposed to many situations involving death and dying.

She is extremely grateful to be working in such an incredible hospital with palliative care and nursing staff that prioritize excellent patient care.

Anna has been extensively involved in ensuring patients have a comfortable and meaningful death. Physiotherapists work closely with other allied health teams as well as palliative care doctors and nurses to ensure patients are able to move, rest and live out their lives as comfortably as possible.

Anna is concerned that many people still do not know that VAD is legal in Victoria and the process in which to access it if eligible.



She also supports families in the acute period following the loss of a loved one. Anna has listened to both good and bad experiences of death and has learnt a lot about the importance of honouring patients' wishes to the best of our abilities.

Anna is also very interested in young people establishing Advance Care Plans and appointing Medical Treatment Decision Makers, as well as signing up to be organ donors.

She is currently completing a 'Masters of Public Health' exemplifying her keen interest in the future of healthcare and improving service delivery.

WHAT DO WE HOPE TO ACHIEVE?

The DWDV Young Ambassador program has only very recently been developed, with ongoing work happening behind-the-scenes to determine goals and a mission statement. This work will hopefully be completed by early 2023, with public facing initiatives coming from that point onward.

Their main aims will be to raise awareness of VAD and its rules/safeguards, to promote a range of end of life options for young people, and to assist with any enquiries from young community members who are interested to know more.

The Young Ambassadors will also be available for media surrounding issues with the current VAD scheme to ensure laws are changed to increase access, where appropriate, and people can die with dignity.



What do you think?

Many of our wonderful members and supporters have already completed our survey on Voluntary Assisted Dying (VAD) in Victoria. The responses to this survey will help to inform our submission to the Parliamentary review of the Victorian Voluntary Assisted Dying Act 2017, which must be conducted in the year commencing 19 June 2023, covering the first 4 years of implementation in Victoria.

If you have not yet submitted a response, we'd love to hear from you about any concerns/issues you have had/are experiencing with VAD since its implementation and how it might be enhanced.

You can find a link to the survey on the home page of our website.

News from Australia ...

There is a lot of good VAD news emanating from Australia.

Territory Rights

First and foremost was the successful passage of the Restoring Territory Rights Bill in the Federal Parliament. This ensured the repeal of the 25-year-old 'Andrews Bill' that had essentially deprived The NT and The ACT of the provision of equal democratic rights, relative to the Australian States. This legislation prevented NT and ACT governments from debating VAD in their respective Parliaments. There had been several prior attempts to repeal the legislation.



Introduced as a Private Member's bill, the debate was carried out in both Houses of Parliament over numerous sittings. The main parties allowed MP's a conscience vote. It is now up to the 2 Territories to draft their own VAD bills.

The ACT Chief Minister, Andrew Barr, has stated he will introduce VAD legislation next year and NT Chief Minister, Natasha Fyles has stated that it won't be until 2024 when legislation will be considered.

Telehealth

In relation to the Commonwealth ban on VAD telehealth consultations, it is hoped this matter will come before Parliament early in the New Year and be resolved.

Meanwhile GP and DWDV Board member, Dr Nick Carr, is seeking a judicial interpretation of the law from the Federal Attorney General and will attend the Federal Court in the second half of May.

Queensland

Queensland prepares for the implementation of their VAD legislation on January 1, 2023. They have appointed a nine member VAD review board.

The Chair of the VAD Implementation taskforce reported that Queensland doctors wanting to help terminally ill patients in regional Queensland will fly out to see them rather than risk fines for discussing VAD via telehealth consultations.

South Australia

Unfortunately, the implementation date of the South Australian legislation was not brought forward. It will commence January 31, 2023. The SA government announced a commitment of \$18 million over a period of 5 years to help with the implementation of the process. An implementation Conference, run by SA Health, was held on November 16.

Tasmania

Voluntary Assisted Dying legislation became operational in Tasmania on October 23, 2022. Catholic healthcare providers have stated that they will not support or facilitate the new VAD laws. It was reported that some Tasmanians will have to wait to access VAD as few doctors have completed the training.

Western Australia

The Western Australian Assisted Dying Board, Annual Report was released in November. This covered the first year of VAD operation in WA. One hundred and ninety VAD deaths were recorded. These deaths comprised 1.1% of all deaths over the period of June 30, 2021- June 30, 2022.

... and Around the World

Belgium

The case of a Belgian woman who was approved for an assisted death, despite not fulfilling the eligibility criteria, was presented before the European Court of Human Rights. The court handed down a decision that there had been no contravention of human rights.



Canada

There has been a continual torrent of anti-assisted dying stories from Canada in recent months, which shows little sign of abating. There have been stories reported of Canadians offered MAiD for non-medical conditions. Poverty, homelessness, and inability to receive adequate health care have been cited as reasons why some have sought an assisted death. In March next year, Canadians suffering from solely a mental illness may become eligible for MAiD. Uproar followed when a doctor, from the Quebec College of Physicians, told a Government Special Joint Committee on MAiD that infants, up until the age of 1, whose prospects of survival were null, should be given access to MAiD. So much wonderful work is being done in Canada but nearly all news reports are currently extremely critical of the proposed expansion of the MAiD eligibility criteria.

China

Shenzhen, China, has become the first city in mainland China to pass legislation, that honours the living wills of critically ill patients, and can lead to the refusal of excessive life-sustaining treatments.

Cyprus

A 75-year-old British man was charged with the murder of his terminally ill wife. She had made her husband promise he would help her to die if she suffered, as her sister had, whilst also dying from leukaemia. The man's charge was reduced from murder to manslaughter. He is currently facing a delay before he formally enters a plea of manslaughter.

France

The French President has announced that there will be a national debate on end-of-life options with an assurance that he has plans to legalize assisted dying by the end of 2023. A panel of 150 randomly chosen citizens will work with health care workers over the coming months and local debates have been organized in regions of France. The President discussed the topic with the Pope, on his recent visit to France.

India

There have been numerous stories from India of citizens who have filed a petition, for an assisted death, before the Indian President. Sadly, many of the individuals have suffered trauma because of socio-economic hardships and lack of access to healthcare. The deaths have not been granted.

Ireland

An assisted dying bill was tabled in the Irish Parliament in 2020 but failed to progress. The justice committee recommended that a special assisted dying committee be established. That was 18 months ago. In late November it was announced that the special committee was to be established within days. This followed the death of tireless VAD advocate Vicky Phelan.

Korea

An assisted dying bill has been proposed in Korea. An expert however argues that more should be put into palliative care and a bill is not required.

Malta

The prime minister of Malta has recently stated that a decision on Assisted Dying may be on the cards in 2023.

New Zealand

A report on how the New Zealand End of Life Choice Act 2019 has operated one year after it was implemented on November 7, 2021, reveals that there had been 294 assisted deaths. The law will be reviewed in 2024. Many, including the sponsor of the Bill, MP David Seymour, think the 6-month prognostic time frame until death is too strict and may be causing unnecessary suffering.

Portugal

Just in, there is great news from Portugal. Portugal's parliamentary MPs have voted 126 to 84 in favour of assisted dying legislation. Some opposition MPs called on the President to send the text for constitutional review. Upon receiving the text, the President can sign it into law, send it for constitutional review or exercise his veto within 20 days. A veto can then be overturned by a majority of members of parliament. This is the third time an assisted dying bill has successfully made it through parliament. However, the earlier two were vetoed by the previous President.

Spain

Assisted dying laws were passed in Spain in 2021. Now with the encouragement of Catholic associations, vehemently opposed to assisted dying, the Church in Spain has decided to create assisted dying free zones.

Switzerland

Professor Sean Davison, former WFRtDS President and VAD provider placed under house arrest in South Africa for 3 years and recently released, has joined Exit International as an Executive Director working alongside Dr Phillip Nitschke. He will take responsibility for the Sarco project, a device used to achieve an assisted death. It is thought that it will become available in Switzerland in mid-2023. Private care homes in the Zurich Canton are how exempted from providing their residents with an assisted death. Switzerland is looking to limit the number of people travelling there for an assisted death.

Netherlands

Dutch activists campaigning for the decriminalization of assisted suicide in the Netherlands have taken the Dutch government to court. They are arguing that the ban on helping a person end their life violates human rights as citizens are denied the right to have a dignified death. There are reports of a backlog of requests for an assisted death. Individuals suffering from mental illness and dementia have waiting times of up to 2 years.

United Kingdom

An assisted dying inquiry has just been announced by the Health and Social Care Select Committee. This will be the first ever House of Commons inquiry into assisted dying. A huge step in the right direction. Meanwhile, Dignitas has accused Westminster of "outsourcing" the problems caused by the lack of assisted dying legislation in the UK, to Switzerland.

Jersey

The principle of assisted dying legislation was approved by MPs in 2021 and more detailed proposals were to become available for debate before the end of 2022. Before the legislation is passed it is required that MPs vote twice again on the bill. This was all consequently delayed by the death of Queen Elizabeth II and a final vote, that was intended to take place in May 2023, has been deferred to April 2024.

Scotland

Dignitas, Switzerland has helped 16 Scots to end their lives. It is backing a bid to legalise assisted dying in the Scottish parliament. Liberal Democrat Liam McArthur has won the right to introduce a bill into the Scottish parliament in 2023.

United States

October 27 was the 25th anniversary of the passing of Oregon's Death with Dignity Act.

Uruguay

The Rio Times reports that Uruguay's lower house has passed a "euthanasia" bill. It now goes to the Senate. If it passes, Uruguay will be the second country in Latin America, after Colombia, to legislate an assisted dying bill.