

Dying with Dignity

New South Wales



NEWS | Winter 2023

5 MONTHS

NSW

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President's Message

In a few short months, the NSW Voluntary Assisted Dying (VAD) Act takes effect. From Tuesday 28 November 2023, terminally ill people in this state will have the right to choose to end their lives quickly and peacefully.

While many of us would have preferred a shorter implementation period, a huge amount of work is needed to ensure that the regime operates as intended and all the necessary processes are in place so that the system works smoothly for patients and healthcare providers.

We have been extremely pleased with the way that NSW Health have approached the implementation. On pages 3, 4 and 5 we give an overview of their activities and introduce some of the key people in their team.

Right from the start NSW Health have been committed to ensuring that the experience of the patient and their carers is as smooth as possible, in what will be a complex and time-consuming process, due to the important checks and balances in the regime.

Critical to the smooth operation of the regime are the VAD Care Navigators who will be vital providers of support and information for patients and practitioners. NSW Health is developing detailed clinical guidelines and recruiting visiting medical officers to help support and educate VAD providers and healthcare facilities. A VAD Pharmacy Service is being set up to handle preparation and distribution of VAD medication. Importantly, NSW Health have been proactive in providing VAD information across the healthcare sector and using their networks across the public health system and GP groups to encourage doctors to become VAD providers. As we know from other states, the lack of doctors willing to provide VAD services has been the main obstacle to access for eligible patients.

Over coming months, the NSW Health VAD website will be updated with increasingly detailed information for patients and practitioners, including about the process of applying for VAD. We will keep you posted on these developments via our email updates.

As part of our commitment to providing education and resources for our supporters on end-of-life issues, we have held two extremely successful

webinars which you can read about on pages 6 and 7. We are thrilled to have brought you such experienced and engaging presenters and it is clear that there is a huge level of interest from our supporters in these topics.

Our next webinar is on Wednesday 2 August 2023 featuring End of Life Doula's and we are planning some VAD-specific sessions as we approach the implementation date. Our webinars are recorded and available via [our website](#) and [YouTube](#).

This edition also includes an update on VAD in other states and territories. With regimes up and running in five states it is clear that the cataclysmic outcomes foreshadowed by VAD opponents have not come to pass. The laws are working safely and effectively. The federal ban on the Territories passing VAD laws has now been overturned with the ACT expected to introduce legislation this year. Sadly, the Northern Territory shows no signs of progress, which is a shame given that it had the world's first VAD law in the 1990s before it was overturned by the federal government.

Internationally, there has been some progress, with Portugal's VAD law finally getting over the line despite the best efforts of its conservative President and France's parliament preparing VAD legislation, after a citizens assembly process supported the introduction of VAD. While laws are being considered in various parts of America, two states with VAD laws in place voted to extend their regimes to patients from other parts of the country. Canada's move to expand its medical aid in dying laws to those with severe and intractable mental illness has been fraught with controversy, as has the removal of the requirement that death be "reasonably foreseeable" which has led to concerns about the application of the regime to those with a disability. Meanwhile, progress in Ireland and the UK appears to have stalled.



As always, thank you for your support,
Penny Hackett

NEWS FROM NEW SOUTH WALES

Not long to go

It is now over 12 months since the NSW Voluntary Assisted Dying (VAD) Bill finally passed into law on Thursday 19 May 2022. The new law will take effect on 28 November 2023, after an 18 month implementation period.

With just 5 months to go until the first person will be able to apply to access voluntary assisted dying in NSW, Dying with Dignity NSW are pleased to report that NSW Health is progressing well through the implementation.

NSW Health's VAD Implementation update

The NSW Health VAD Implementation Team is part of the Office of the Chief Medical Officer, Dr Kerry Chant and it includes dedicated staff working across policy, clinical and communication fields. Leading the team are Antoinette Sedwell and Dr Wade Stedman.

Senior Manager, Antoinette Sedwell is a psychologist and Lead for voluntary assisted dying implementation in NSW. Antoinette oversees the development of key deliverables required to support the implementation of voluntary assisted dying. Prior to leading this work, Antoinette had many years' experience working at NSW Health and the Agency for Clinical Innovation leading the development and implementation of numerous policies and programs in both drug and alcohol and mental health.



Antoinette Sedwell

Dr Wade Stedman is the Clinical Lead for the implementation of voluntary assisted dying in NSW, including development of clinical guidance, education and training and clinical pathways. Wade is also a staff specialist in intensive care medicine at Royal North Shore Hospital, provides simulation education, and has a particular interest in long term psychological outcomes of patients who survive a severe critical illness.



Dr Wade Stedman

Webinars

Over the past six months the Implementation Team have held a number of well-attended webinars for NSW Health staff, general practitioners, pharmacists, Aboriginal health care workers and organisations, private hospitals, aged and disability care services and community groups.

The webinars provided an overview of the NSW voluntary assisted dying process, patient and practitioner eligibility criteria and the approach NSW Health are taking to consultation.

Each webinar included time for participant questions and recordings of each webinar were circulated to those who registered.

Advisory and Working Groups

The Team is working closely with a range of groups to ensure that resources and clinical guidelines are ready for commencement:

- **The Clinical Advisory Group** is responsible for providing advice to NSW Health on clinical matters relating to voluntary assisted dying. The Advisory Group includes representatives across a range of specialty areas and geographic regions.
- **The Consumer Engagement Advisory Group** provides a mechanism for information sharing with consumers and communities, and an opportunity for targeted consultation on consumer engagement, messaging and information. The Advisory Group includes members representing priority groups including Aboriginal people, culturally and linguistically diverse communities, older and younger people and people who live in rural and remote areas. Our CEO, Shayne Higson is a member of this group.
- **The Health Ethics Advisory Panel** is an existing multi-disciplinary panel with expertise in health ethics, clinical practice, consumer concerns and community issues which is providing guidance on ethical considerations of voluntary assisted dying.

NSW Health is also working closely with local health districts and other Health agencies to establish care pathways to support eligible patients across NSW to access VAD, if this aligns with their goals of care.

NSW Health VAD Conference

The Team will be hosting a conference for health professionals on Friday 29 September. Taking place two months before commencement, the conference is an opportunity for health professionals to learn more about voluntary assisted dying, hear about the experience of other states and register interest in becoming a VAD practitioner. The conference will be held at the International Convention Centre Sydney.

Recruitment

The Team have also been busy recruiting members for the VAD Board, the NSW VAD Care Navigator Service, the Statewide Pharmacy Service and other key roles.

The VAD Care Navigator Service provides a service to assist people considering voluntary assisted dying, their family, friends and carers, health practitioners and health service providers to navigate the voluntary assisted dying pathway.

The VAD Care Navigator Service will:

- provide information and support to patients and other community members with questions about or wishing to seek access to VAD.
- support queries from practitioners and coordinate ongoing training and support for coordinating, consulting and administering practitioners
- advise patients how to raise voluntary assisted dying with their clinical care team and, in some circumstances, connect them with coordinating, consulting, and administering practitioners.

Julie Letts – Voluntary Assisted Dying Care Navigator Service Manager

Julie has over 40 years' experience in the Australian public health system in clinical, management, policy and ethics-related roles. She also managed a large surge call centre during the Delta wave of COVID-19.

Throughout her career, from ICU work managing dying patients, to developing foundational end-of-life decisions policy for NSW Health, and training as a funeral celebrant, she has been motivated to improve the experience of death and dying.



Julie Letts

The Voluntary Assisted Dying Pharmacy Service will be responsible for coordinating the safe procurement, supply and disposal of the voluntary assisted dying substance across NSW.

The Pharmacy Service will support patient access to the voluntary assisted dying substance regardless of their setting. For example, the patient may be in their home, at a residential care facility or a public hospital.

Suzie Olding – Voluntary Assisted Dying Pharmacy Service Manager

Suzie has many years' experience as an emergency pharmacist and a pharmacy team leader, in NSW at Royal North Shore Hospital and in Victoria. She has a particular interest in delivering new pharmacy programs and upskilling pharmacists into advanced practice roles, having previously implemented programs for collaborative pharmacist prescribing and pharmacist attendance at acute stroke codes.



Suzie Olding

Visiting Medical Officers

The first Visiting Medical Officers (VMOs) have been recruited as part of the Voluntary Assisted Dying Access Service which is part of the VAD Care Navigator Service. They will support the implementation of voluntary assisted dying and, upon commencement, support people to access voluntary assisted dying. This is in addition to eligible practitioners who may apply to become authorised voluntary assisted dying practitioners as part of their role within the public system or in the community.

The VMOs for voluntary assisted dying will:

- assist in the development of resources and education and training materials
- be available to support education and training across NSW
- support access to voluntary assisted dying services for people in a range of locations, such as hospitals, private homes and residential facilities
- supplement provision of voluntary assisted dying services across NSW – particularly to regional and rural areas, as required from 28 November 2023.

NSW Health delivers keynote address to General Practitioner Conference

On Friday 19 May 2023, Clinical Lead Dr Wade Stedman and Senior Manager Ms Antoinette Sedwell spoke to over 500 GPs at the General Practice Conference and Exhibition (GPCE) about voluntary assisted dying.

GPs are an important and trusted voice for patients, including during end of life care, and this was an important opportunity for GPs to learn about the intersection of VAD and primary care.

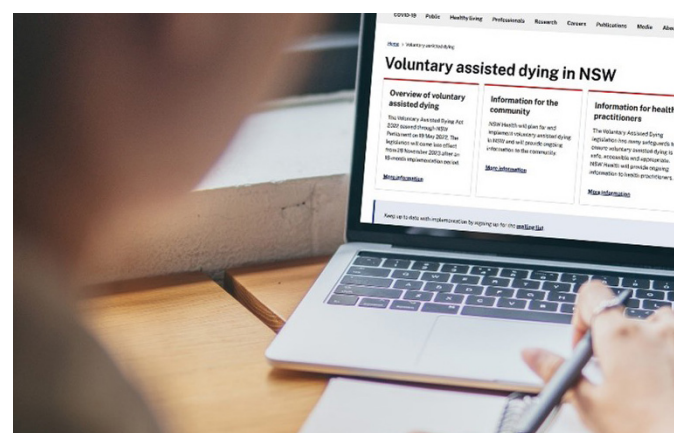
While a patient cannot access VAD before 28 November, GPs and other practitioners are able to provide general information including around patient eligibility, and advice on all end of life care options including palliative care and VAD.

New information on NSW Health website

The [NSW Health Voluntary Assisted Dying website](#) has been updated to include further information on clinician participation in voluntary assisted dying, the care navigator and pharmacy services, and the key advisory groups informing implementation.

Health practitioners can also learn more about training packages under development and the formal roles involved in the voluntary assisted dying process.

Over coming months more detailed information for patients and carers will be added to the website so make sure you continue to check [the website](#) for updates in the lead up to the commencement of VAD in NSW on 28 November 2023.



Dying with Dignity NSW will maintain a close relationship with the VAD Implementation Team and we thank them for allowing Dying with Dignity NSW to share their update.

DWD's End-of-Life Webinars

In our last newsletter, we presented the new strategic plan for Dying with Dignity NSW that would guide our activities from 2022 to 2024.

The strategic plan was developed around four key pillars – Support, Educate, Engage and Defend. As part of our goal to educate supporters and the general public, we planned to provide a series of webinars on end-of-life topics. We have been delighted with the response to our first two webinars and are excited to announce the third webinar to be held on Wednesday 2 August 2023.

The Importance of Advance Care Planning

On Thursday 2 March we hosted our first webinar on [The Importance of Advance Care Planning](#) with special guest speakers - Professor Colleen Cartwright and Nurse Anne Mellor. Over 300 people took part in this informative webinar and for many it was a huge relief to get accurate information on this topic.

Although by the end of 2023 eligible people living in NSW will be able to access the new VAD law, for most people, Advance Care Planning (ACP) will still be the most effective way to ensure that your loved ones and health providers know what matters most to you and respect your treatment preferences.

Both speakers gave excellent presentations before we opened up the conversation taking questions from the audience. Many important points were raised.

Australians are, on average, living longer than at any other point in history. Every year, advances in

medical treatments are providing new options to prevent, manage, or cure illness. With more people surviving illnesses that would have been fatal in the past and increasing options for future care, ACP is more important than ever. ACP is based on the fundamental principles of self-determination, dignity and the avoidance of suffering and is integral for delivering person-centred care.

Professor Cartwright said that many older people fear what their life and care will be like at the end stage of their life and, according to three studies, loss of mental faculties (especially from dementia) is top of the list, not just in relation to terminal illness but also in relation to growing older. But as Professor Cartwright pointed out -

- Approx. 8% of people aged 65+ have dementia: which means that 92% do not!
- Approx. 20% of people aged 75+ have dementia: which means that 80% do not!
- Approx. 40% of people aged 90+ have dementia: which means that 60% do not!

However, older people are often treated as if they have dementia, and their fear is real. Advance care planning helps to address these fears and concerns.

With over 1,000 registrations for our ACP webinar, it is not surprising that over the past three months more than 1,000 people have viewed the recording and hundreds have downloaded the ACP documents and advice found on our website.

We thank Professor Colleen Cartwright and Anne Meller for their commitment to end-of-life planning and their generosity in sharing their knowledge and expertise during the event and also when responding to some follow-up questions from members and supporters.



The Importance of Advance Care Planning



Professor Colleen Cartwright

**Recording
now
available**



Nurse Anne Meller

Dying with Dignity
New South Wales

Empowering the Elderly - How to Avoid the End-of-Life Conveyor Belt

On Wednesday 17 May 2023 we hosted the second webinar in our series on end-of-life issues titled - [Empowering the Elderly - How to Avoid the End-of-Life Conveyor Belt](#).

With two very experienced guest speakers, Professor Ken Hillman AO and Associate Professor Gideon Caplan, DWDNSW CEO, Shayne Higson led the discussion on the challenges facing the elderly and their loved ones as end of life approaches and how they can best navigate the medical system in the last months, weeks or days to ensure that a person's wishes are respected.

Many elderly people linger in pain and confusion in ICU when all they want is to die at home in peace, with their loved ones. ICU can be a place where the frail, soon-to-die and dying are given unnecessary operations and life-prolonging treatments without their wishes being taken into account. We need to be better equipped and emboldened to ask about the options that doctors in hospital should offer us but mostly don't. There are other, gentler options for patients that can be much more sympathetic to the final wishes of most people facing the end of their lives.

Professor Hillman has worked in intensive care for 40 years and over that time he has seen enormous changes. When he first started his patients were mainly younger people with a single problem such as severe trauma or severe infection. Over time intensive care specialists developed amazing ways to keep people alive - drugs, machines etc so it is, in fact, very difficult to die in intensive care.

But over the 40 years, doctors have been tempted to use these machines and drugs in ways that

they were never intended. It is easier for doctors to keep people alive rather than allow them to die.

Professor Hillman and our second expert speaker, Associate Professor Caplan, Director of Geriatric Medicine at Prince of Wales Hospital, focused on the frail elderly in this webinar, so not people with cancer or other life-threatening diseases. Using hypothetical scenarios they explained how we have arrived at the current fall back position where when a frail, elderly person gets very sick or has a fall, the ambulance is called, the person is taken to emergency before being admitted and they often end up in intensive care. They explained how difficult it is for family members to make important decisions at this time, especially when doctors use certain language.

While many of our participants in the webinar may have the courage to say, "No, my mother would not want more treatment, she would prefer to die peacefully," according to Professor Hillman that is not the case for most in our society. When confronted by this emergency, loved ones tend to say, "Please do everything you can to save them," so it can be difficult to pluck these people off the conveyor belt.

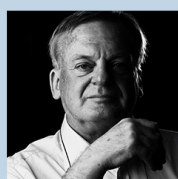
Despite having data that can reliably predict when elderly, frail people are nearing the end of their life, doctors are reluctant to say they are "terminally ill" which is why they are on the conveyor belt.

With over 1350 registrations, 550 people participating and nearly 500 people having watched the recording so far, we wish to thank Ken Hillman and Gideon Caplan for their contribution. The recording can be watched via [our website](#) and our [YouTube Channel](#) here.



Empowering the Elderly

How to avoid the end-of-life conveyor belt



Professor Ken Hillman

**Recording
now
available**



Professor Gideon Caplan

Dying with Dignity
New South Wales

Upcoming Webinar

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.

The third webinar in our end-of-life series titled '[End of Life Doulas - Bridging the gaps in care](#)' will be held on **Wednesday 2 August 2023**. We look forward to hearing from three End of Life Doulas who offer reassurance, support, options and education, allowing people to make informed choices that align with their values, wishes, and needs, take back control and live their life as they choose. An end of life doula supports life!

Helen Callanan

Helen Callanan is a practising End of Life Doula and the Founder, Managing Director and Lead Educator of Preparing the Way. Trained in Traditional Chinese Medicine and Reiki and with more than 30 years of experience working with the very ill and dying, Helen has deep insight into health and healing.

The long term caring and death experiences of her parents, family, friends and many clients alongside her passion for education that transforms, led

Helen to establish Preparing the Way in 2014 and bring her wealth of knowledge to hundreds of doulas, clients and their families and those close to them.

Jancine Hurst

Jancine Hurst is an End of Life Doula on the Sunshine Coast, Queensland, specialising in holistic end of life and after death care. She supports those nearing end of life and their families by sharing available options so they can make end-of-life choices that best align with their values and preferences.

With a background spanning over 30 years in childcare, aged care, and end of life care, Jancine understands that it takes courage and compassion to lean into life limiting, terminal and ageing illnesses.

Carolyn Vaughan

Carolyn Vaughan is a practicing End of Life Doula in the Illawarra region of NSW. Her work is informed and enriched by qualifications in Early Childhood Education, Aged Care, Somatic Therapy and ongoing study in End of Life Care.

Carolyn uses her extensive lived and professional experience and skill to engage with communities and individuals, inspiring conversations that explore the topics of death and dying and the choices and decisions that we can make to enhance and honour our end of life journey.

To register [click here](#).

End of Life Doulas - Bridging the gaps in care

5pm on Wednesday 2 August 2023



Helen Callanan



Jancine Hurst



Carolyn Vaughan

When and how can someone access VAD in NSW?

The NSW Voluntary Assisted Dying (VAD) Act will take effect on 28 November 2023. This means terminally ill residents in NSW still need to wait another five months before they can access VAD. The past 13 months have been extremely challenging for those of us who have received calls from people who needed to access the new law sooner but as we explained last year, there has been a lot of planning and implementation required to make sure the regime operates in accordance with the Act and that both patients and practitioners are very clear on the process.

However, in less than five months, people who are experiencing intolerable suffering at the end of their life, and who meet the strict eligibility criteria, will be able to follow the highly safeguarded process and hopefully access VAD, if that is their wish.

Like all Australian VAD laws, the NSW Voluntary Assisted Dying Act is a very detailed piece of legislation. Readers can view the full, 84-page document on our website here – NSW Voluntary Assisted Dying Act.

Although we provided the following information in our last newsletter, we feel that it will be useful for everyone to have this information again.

Here is a summary of the main eligibility criteria and some of the key safeguards within the process.

ELIGIBILITY CRITERIA

For someone to be able to access VAD in NSW, they'll need to meet the eligibility criteria, which are:

- They must be an adult (18 years and older), who is an Australian citizen, a permanent resident of Australia, or has been resident in Australia for at least 3 continuous years.
- They must have been living in NSW for at least 12 months.
- They must have at least one disease, illness or medical condition that is advanced, progressive that will, on the balance of probabilities, cause their death within six months (or within 12 months

disease), and is causing suffering that cannot be relieved in a way the person considers tolerable.

The person must have decision-making capacity in relation to voluntary assisted dying.

- The person must be acting voluntarily.
- The person must not be acting because of pressure or duress.
- The person's request for access to voluntary assisted dying has to be enduring.

THE PROCESS (KEY POINTS)

- In order to access this compassionate, end-of-life choice, the dying person themselves must make the request. It cannot be made by a family member, a carer or anyone else.
- A request cannot be made in an advance care directive because the person has to have decision-making capacity throughout the whole process.
- The person has to make three requests and one has to be in writing.
- There has to be two witnesses to the written request.
- Assessment of criteria for access has to be carried out by two independent medical practitioners who have to meet minimum requirements regarding their qualifications and experience and they have to have done special VAD training.
- All doctors will be trained in recognising the signs of pressure or duress and if they are unsure whether a patient is acting voluntarily, or whether pressure or duress could be a factor, they must refer the patient to someone who has the skills and training to make a determination. This could be a psychiatrist, psychologist, social worker or the police depending on the circumstances.

To view the full Voluntary Assisted Dying Act 2021 visit our website at - <https://dwdnsw.org.au/nsw-vad-legislation/>

As mentioned earlier, in the update on VAD Implementation from NSW Health, as soon as the VAD Care Navigator Service is up and running, the navigators will be the best people to contact for all enquiries related to eligibility, how to access the new VAD law, how to find VAD trained doctors etc.

We will also continue to provide monthly updates as the implementation date approaches.

NEWS FROM AROUND THE COUNTRY

The Territories

ACT - Following the repeal by the Federal Parliament of the 1997 Euthanasia Laws Act at the end of last year, the ACT government acted quickly to initiate community discussion with those in the movement for change to legalise voluntary assisted dying (VAD), initially by consulting a group of experts and highly involved participants from around the country and in the ACT. They then gave ACT community members a period of some months early this year to make submissions about how they wanted VAD to operate in the ACT.

The discussion paper presented by the government for those interested in making a submission to consider was based largely on the legislation already in existence in the states but with questions around various contentious issues such as eligibility requirements, location eligibility, involvement and qualifications of doctors and etc. The time for making submissions closed at the end of April. The stated wish of the ACT government is to pass legislation by the end of this year.

Since then there has been some discussion in the media on radio and television to prepare the community for this change to legislation. In a recent interview on ABC television news, Tara Cheyne, the Minister responsible for overseeing the legislation, stated that she did not think that it was necessary for dying children under the age of eighteen to be excluded from a voluntary assisted dying law and that the ACT Government would develop its own hospice.

These public statements give us some hope that the legislation will meet the end of life needs of most ACT citizens. Whether the legislation will be consistent with the ACT Human Rights Act is a question that will only be answered when we see the legislation that is passed by the ACT Government.

Jeanne Arthur, President, DWD ACT

Northern Territory - Unfortunately, there is still no progress in the NT in regard to law reform since the Chief Minister announced she would not be touching VAD until after the next election on 24 August 2024. **Judy Dent, President, NTVES**

Western Australia

Dying with Dignity WA holds the view that although their VAD Act was a great achievement at the time, and was certainly an improvement on the Victorian law that had passed two years earlier, it is a model that offers VAD to only some of those in need.

When it passed in December 2019, it did fall short of the recommendations made by their Parliamentary Joint Select Committee, moreover, experiences in WA, and in other states, have shown that the fears whipped up by opponents were completely overblown. According to DWDWA President, Steve Walker, WA's VAD scheme operates well overall, and safely, but can and should be improved.

“Various innovations introduced in VAD laws passed by other states since 2019 are sensible and should be adopted here. Ultimately our objective should be a safe, workable and accessible model of VAD for all Australians, including in the Territories, which is as consistent as possible across borders,” he said.

The VAD Board itself presented some recommendations in its first annual report in November 2022, however, they did not include any of the important concerns raised by DWDWA members which go to the fundamentals: things like eligibility based on estimates of the time remaining to death, and the failure of the Act to permit people of sound mind to stipulate in an advance health directive that they want an assisted death.

“These are not easy questions to address, but it is important that they be grappled with,” said Mr Walker.

DWDWA welcomed a comment from the former WA Premier a few months ago, that he welcomed a national conversation about allowing those diagnosed with dementia to be considered eligible for VAD.

The failure of Australian legislation to deal with dementia has also been highlighted in some recent articles in The Age.

Steve Walker, President, DWDWA

South Australia

Twelve South Australians have chosen Voluntary Assisted Dying (VAD) to end their suffering in the first three months since commencement (January 31). An additional 16 people received a VAD Permit, meaning all steps have been completed and they can notify their Coordinating Medical Practitioner when they wish to have the VAD substance supplied.

The first quarterly report from the VAD Review Board showed - 12 people received the VAD substance; 7 people had cancer and 5 had a neurodegenerative disease; 7 people were in their 70s; 7 people were male, 5 were female; 9 people died at home and 3 in a hospital; 9 people were in a palliative care program; 10 people lived in metropolitan Adelaide and 2 people in the regions; 28 VAD Permits were issued; 20 were for self administration and 8 for practitioner administration; and the average time from first request to receiving a VAD Permit was 25 days. The report includes quotes from six users and family members showing their appreciation for people who advocated for VAD and those who now provide it. The SA Health VAD Report acknowledges the work of VADSA in raising community awareness and looks forward to continued cooperation between VADSA and SA Health in this role.

VADSA

Tasmania

Tasmania's End-of-Life Choices (Voluntary Assisted Dying) Act 2021 came into effect on 23 October 2022. On 10 March the VAD Commission released an update stating that in the first four months of operation at least five terminally ill Tasmanians had ended their life by accessing the new law. Twenty four formal first requests from individuals were made and of those, 11 progressed to the point where medical practitioners were given authorisation to access the VAD substance for the individual. The Act is continuing to operate as intended and the safeguards applied through the legislation are working.

Hilde Nilsson, President, DWDTAS

Queensland

The Queensland Voluntary Assisted Dying law became a reality in January 2023. Since the implementation, Dying with Dignity Queensland (DWDQ) have been busy resourcing supporters and others – making sure they know where to find information about the new law, emailing a brief monthly update to supporters, giving talks to community groups and developing a webinar which they will use to take information to more remote communities. DWDQ met with their State care navigator service to discuss how they can help with their work. They have also been refreshing their website and using social media to highlight some of the incredibly positive experiences that people have shared about VAD. Having that choice, as we know, brings a sense of comfort and calm for all.

In May the Sunshine Coast co-ordinator took part in a memorial for Joan Rae, one of the earliest advocates for VAD in Queensland. "It was good to honour her steadfast work as we welcome new choices for end of life care and a new phase for the work of DWDQ."

Sheila Sim, President, DWDQ

Victoria

Dying with Dignity Victoria have been preparing for the Review of their VAD Act, maintaining close contact with our DWD colleagues in WA, who face a review of their legislation at the same time.

As many readers may recall, the passing of the Victorian legislation back in 2017 required some significant changes during the debate as a result of being the first state to pass these laws. DWDV will claim that the passage of time, and the implementation of VAD laws across the country, has reduced the anxiety over hypothetical risks.

Fortunately, the reports from the VAD Review Board have noted complete compliance in all but a very few trivial and inconsequential cases so DWDV considers it appropriate to lobby for the removal of obstacles that have impacted access for some terminally ill individuals.

Hugh Sarjeant, President, DWDV

WHAT'S HAPPENING OVERSEAS

Canada

As we have reported previously, Canada is in the forefront of developments in voluntary assisted dying and is currently engaged in impassioned and divisive debates about the wisdom of various extensions to their medical aid in dying (MAiD) scheme. Canada's MAiD system came into force in 2016 and between 2016 and 2021 (the last year for which we have a report), 31,664 people died a medically assisted death. Quebec has the highest proportion of medically assisted deaths in the world with 5.5% of deaths in this category. The next highest country is the Netherlands, with 4.4%.

The biggest bone of contention in Canada is whether MAiD should be expanded to include those with only a mental disorder. This was due to happen in March 2023, but because of the huge controversies surrounding the issue, it has been postponed until March 2024 to allow more time to draw up protocols to help assessors make the judgment about whether the mental disorder is untreatable and incurable. The Canadian law requires that a patient "be in an advanced state of decline that cannot be reversed and experience unbearable physical or mental suffering from the illness, disease, disability or state of decline that cannot be relieved under conditions that she/he considers acceptable".

The MAiD law was brought in under the regime of Justin Trudeau and his Liberal government. Now the opposition party, the Conservatives, have introduced a bill into the Federal Parliament to repeal the extension of MAiD to those with only a mental disorder. This is an indication that were they to gain government at the next election they might re-examine the whole system.

There has also been a fierce debate about how MAiD relates to people with disabilities. The original Canadian law specified that "death must be reasonably foreseeable", but when that provision was removed from the law in 2021 as a result of a Quebec court case, that left the way open for people with disabilities whose death was not foreseeable, but who nevertheless,

were suffering unbearably and with no hope of improvement to access MAiD. This led to allegations that people with disabilities who lacked adequate social provision (suitable housing, appropriate support services etc.) were being approved for MAiD. It also led to an outcry from disability advocates that the worth of people with disabilities was being devalued.

The Special Joint Committee of the Parliament which made the recommendations about the treatment of the mentally ill and the disabled also recommended that the parliaments consider extending MAiD to "mature minors" and to allow advance requests for MAiD from those with dementia. These highly controversial issues have been rather overshadowed by the arguments about the mentally ill and the disabled, but it is safe to say that when parliament turns its attention to them, there will again be a huge and divisive debate.

Quebec has a separate VAD law from Canada as a whole, and in early June a new law was adopted that expands access to medical aid in dying and allows advanced consent for the procedure. The new law will permit people with a serious and incurable disease, such as Alzheimer's, to apply for an assisted death before their condition deteriorates and prevents them from consenting to one. However, it could take up to two years for such a request to be processed. The person must have a serious and incurable illness; they must then make a free and informed request describing the extent of the suffering they would no longer wish to tolerate. Once the patient is incapacitated by their illness, two professionals would have to agree that the patient is experiencing the level of suffering they described in their request before MAiD can be administered.

Portugal

We have been watching Portugal with interest, as over the last couple of years legislators have made no fewer than five attempts to get an assisted dying law passed. The first four times the president, who is personally deeply opposed to VAD, refused to sign the bill into law and sent it to the Constitutional Court for review.

The fifth time it was passed he had “run out of vetoes” according to the Portuguese constitution, and finally signed it into law. However, commentators predict that this will not be the end of the matter. Portugal remains deeply divided on the question, and already Catholic doctors are saying they will not collaborate with the law, to the extent of refusing to participate in the implementation process. Under the law’s provisions, people aged over 18 will be allowed to request assistance in dying if they are terminally ill and in intolerable suffering. It will only cover those suffering “lasting” and “unbearable” pain, and people need to be deemed to be mentally fit to make such a decision.

France

In France things have moved along since President Macron announced after his re-election in 2022 that he would like France to have an assisted dying regime like Belgium’s. He established a Citizens’ Convention to make recommendations on a system for France. He said that France must improve the availability of palliative care and there would be a draft assisted dying bill by the end of the summer. The bill would build on the work of the group of 184 randomly appointed French citizens who have debated the issue since December. 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. France’s national council of doctors, l’Ordre des Medecins, has said it opposes involving doctors in helping people kill themselves.

United Kingdom

In the United Kingdom and Ireland, things are still moving at a snail’s pace, as reported in the last newsletter. The UK has made a bit of progress with a parliamentary committee currently taking evidence and submissions on whether the UK should have a VAD law. VAD advocates are running a very spirited campaign in favour and the media is largely supportive. There have been many documentaries and fictional programs which demonstrate a very sympathetic view of VAD. But the parliament does not seem eager to move to a debate on the issue, and it doesn’t seem to have any traction with the Conservative leadership of the government, so we will be surprised if there is

a bill any time soon.

In Ireland a bill has been before the parliament for well over two years, but it has not progressed. The Oireachtas (Irish parliament) has established a committee to examine the question and to recommend improvements to the bill, but it has only met a couple of times this year, and shows no enthusiasm for the task.

In Scotland, there has been a change of leadership with a new Chief Minister, who, unlike Nicola Sturgeon, is not in favour of VAD. Liam McArthur’s bill is still before parliament and McArthur has been consulting widely on the substance, but there is no progress to report. Meanwhile the Churches in both Scotland and Ireland are campaigning vigorously against VAD, as you would expect, and at the moment, their voices are louder. However, in Scotland at least there are a few rays of hope. Recently a group of Professors of Ethics from Scotland’s leading universities came out in favour, and also commissioners at the General Assembly of the Church of Scotland voted in favour of exploring more deeply the diverse views held by Kirk members on the controversial subject, rather than simply agreeing on a position of opposition.

USA

In the United States two states – Vermont and Oregon – are now allowing people from out-of-state to access their VAD scheme. Many more states, are making promising progress in VAD law reform including Connecticut, Massachusetts and Florida but there has also been disappointment. In Nevada, patients and VAD advocates suffered a significant setback on June 5, when Republican Gov. Joe Lombardo vetoed Bill SB239 despite it passing both chambers.

New Zealand

In New Zealand the Ministry of Health issued a report on the first twelve months operation of New Zealand’s End of Life Choice Act 2019.

In the period from November 2021 to November 2022 661 applications for VAD were made, 68% because of a cancer diagnosis. Of these 257 people actually had an assisted death with 82% of these deaths occurring at home. A total of 147 medical practitioners have registered as VAD providers.

BOOK REVIEW - GOOD DEATH THROUGH TIME

Good Death Through Time

Author: Caitlyn Mahar

Publisher: Melbourne University Press, 2023

This history of dying, pain, medicine, law, sociology and euthanasia, most especially in Britain and Australia since the early nineteenth century is a really good read. The main lesson to emerge from Mahar's book is that attitudes to and laws about 'the good death' have changed over the last two centuries with increasing secularisation, a growing fear of modern, medicalised dying and our increasing cultural emphasis on patient autonomy and individual rights.

'At the heart of the story of euthanasia is a remarkable reconception of what it means to die well in the West'
(p. 8)

This excellent piece of scholarship traces the history of euthanasia from the early nineteenth century, when 'dying was infused with a religious sensibility' (p. 14) through the upsurge of support principally from members of the medical profession prior to WW2, through the downturn in support following revelations of the Nazi program, and the involvement of members of the medical profession in the Holocaust, then through the post-war period to the Rights of the Terminally Ill Act 1995 in the Northern Territory, the first legislation in the world that allowed doctors to actively assist terminally ill patients to die, to the backlash against this law at the Federal level in Australia, and on to the passage of state-based laws in Australia from 2017 in Victoria up until the present day. It is a fascinating journey.

Caitlin Mahar's Good Death Through Time is based on her award-winning PhD thesis on the history of euthanasia awarded by the University of Melbourne in 2016. It has been updated for this publication and published in February 2023. This most impressive author, Caitlin Mahar, currently works as an academic historian at Swinburne University in Melbourne.

However, like any piece of scholarship this book

has its limitations. First, the book is based on primary and secondary sources accessed in libraries and archives in two countries only: Australia and the United Kingdom. So, the analysis reflects this anglophone and British bias.

In addition, this history relies on written sources, in the absence of interviews, or oral history. As a consequence, it tends to privilege the experiences and views of the more influential members of society: doctors, theologians, politicians, academics and lawyers in particular, rather than members of the broader community as such. Having said that, Mahar does pay particular attention to the views of those groups more likely to have serious reservations about voluntary euthanasia: Jewish people, people with disabilities, and First Nations Peoples in particular.

The chapter on euthanasia and eugenics in the early twentieth century is particularly enlightening, especially as it presaged establishment of the first euthanasia legalisation organisation in the world in England, from within the medical establishment, in the 1930s, and subsequently the first Voluntary Euthanasia Bill, in 1936.

In 1935, at establishment of the Voluntary Euthanasia Legalisation Society, Charles Killick Millard, a distinguished physician and public health officer, and the driving force behind this pioneering organisation, proclaimed at the inaugural public meeting of the Society:

"the pains of Purgatory and Fires of Hell have ceased to terrify," this modern fear of death centred on more earthly terrors: not the possibility of damnation but the physical and mental pain associated with dying' (p. 63)

The most tragic case of 21-year-old Karen Ann Quinlan, in the USA in 1975, whose parents gained legal permission to remove her from a respirator, and who then lived a further nine years in a coma, revitalised voluntary euthanasia societies in the Netherlands, Japan and Australia in the 1970s, initially in Victoria in 1974, and then in NSW and elsewhere in Australia.

Mahar's Epilogue brings us to the present day. Perceptively she contends that while euthanasia and palliative care have become more differentiated since the 1950s, she leaves us in

no doubt that they are both products of the same radical transformation in Western attitudes to dying and suffering'. Yes, attitudes have changed, 'what is distinctive is the way in which fear has changed' (p. 138).

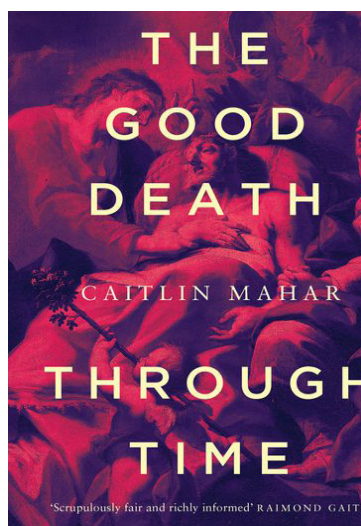
When we look back over two hundred years in the West, we see less authority rested in the church as the nineteenth century unfolded, and challenges to the authority of the medical establishment since the 1970s.

Over the last 100 years, since 1936, with establishment of the first euthanasia legislation society in England, we have placed increasing authority in the state, in democratic institutions and the legislative process. So, organisations like Dying with Dignity NSW have a key role to play, as we provide a voice for lay people, patients and citizens in these democratic institutions and processes. Mahar posits that contemporary voluntary assisted dying legislation reflects a predominantly white, middle class, ableist, cultural and historical milieu. Is there any truth to this claim? I'm not convinced, but it does put the onus on us to incorporate and respect the views of our complex differentiated society.

What does the future hold? An ongoing progressive historical trajectory that emphasises patient autonomy and increasing reliance on democratic institutions, the state and our legislators to sort out our differences and preferences? Or perhaps push back from conservative religious institutions or the medical establishment?

I recommend Good Death Through Time very highly. It certainly illuminates our path ahead.

By Dr Stephanie Short, Director of DWDNSW



OTHER NEWS

NIA SIMS OAM

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

Nia was recognised for service to community health which included her advocacy for voluntary assisted dying as well as her work at Scleroderma Australia, as a disability advocate and as a registered nurse.



Nia Sims (right) with fellow VAD advocates, Jane Morris and the late Dr Rodney Syme AM

As the End Nears

Compassion & Choices is an advocacy organisation in the USA dedicated to improving care, expanding options and empowering everyone to chart their end-of-life journey. To help people who need practical information about illnesses that they or a loved one are living and dying with, Compassion & Choices have produced a webinar series titled 'As the End Nears'. In these webinars they discuss the final stages of multiple illnesses impacting millions of Americans. Although some of the information relates specifically to end-of-life care in USA, many Australians may find the honest, expert opinion helpful. The first webinar 'As The End Nears - Dying of Heart Failure' covers the final stages of living with heart failure, including treatments, symptoms and the physical experience. The second covers dying of kidney failure. They can be found on [Compassion & Choices' YouTube](#).

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