

### NEWS | Winter 2020



## **News Highlights**

President's Message	2
Making a Bequest	3
The Impact of COVID-19	4
Nia's Story	6
Terminal Sedation vs VAD	8
Interstate News	10
International News	12
Regional and Other Groups	14
HPAD Choice	15
Make a Donation	16

#### DYING WITH DIGNITY NSW

PO Box 25 Broadway NSW 2007 p: 02 9212 4782 e: dwd@dwdnsw.org.au w: www.dwdnsw.org.au JOURNAL – ISSN 0813-5614

#### **President's Message**

Disappointingly there isn't much to report from NSW but the second half of 2020 will hopefully see action in New Zealand and Tasmania and we will be doing whatever we can to help their campaigns.

New Zealand passed its End of Life Choice Act in 2019 on the condition that it be put to the electorate in a referendum at their next election on 19 September. It is by no means certain to pass as voting is not compulsory in New Zealand and the opponents are campaigning hard to defeat it. If you have friends and family in NZ please ask them to Vote YES and if you are eligible to vote in NZ, please register to cast an overseas vote. For the NZ referendum to fail would be devastating for our cause in Australia (see page 13).

Tasmania looks likely to debate Independent MP Mike Gaffney's VAD bill in the next few months. It is wonderful to see strong support from Tasmanian Labor MPs and also from a couple of key MPs from the conservative side. However the Australian Christian Lobby has already fired several shots in its battle against the bill claiming that it promotes "hopelessness and fear" (see page 10).

Queenslanders go to the polls in October. The future of VAD in that state depends on the election of MPs who support VAD and campaigning has been focussed on flushing out the views of sitting MPs and candidates on assisted dying laws so that voters can be fully informed when they go to the ballot box (see page11).

As you will know, DWDNSW has made this an important part of our campaigning during federal and NSW state elections, preparing VAD scorecards in key electorates, most recently in the Eden-Monaro by-election (see page 5).

On a brighter note, we celebrated the first anniversary of the historic Victorian VAD laws coming into effect on 19 June 2019, giving us an opportunity to reflect on the massive achievement in getting the law through the Victorian Parliament. It was a testament to the dedication and hard work of so many people over so many years and we owe them a huge debt of gratitude for having "broken down the doors" for VAD in this country. Surely other states and territories will follow, allowing all Australians the right to access these compassionate laws.

One person who may one day take advantage of VAD laws in Victoria is the lovely Nia Sims whose story is featured on page 6. Nia has a rare and disabling condition with a grim prognosis and has also witnessed the shocking death of her father from brain cancer. His was one of the stories which featured prominently in the Victorian VAD campaign to help show MPs and the community the horrific suffering which some people experience at the end of their lives, even when they have the best available palliative care.

Nia's dad was given terminal sedation which is palliative care's "treatment of last resort" and essentially puts the patient into an induced coma while "nature" takes its course. In many instances the patient dies from starvation or dehydration. It is generally only offered in the very last days of life when a patient's suffering cannot be relieved by other methods. On Page 8 Doctors Peter Beahan and Richard Lugg give an overview of this practice and compare it with voluntary assisted dying.

Finally, thanks to everyone who participated in our virtual AGM on 13 June. Despite recent setbacks, we will surely get through this COVID-19 crisis and hopefully be able to meet in person in 2021.

Stay safe everyone and, as always, thank-you for your continued support.



As always, thank you for your support,

Penny Hackett President, DWD NSW

### Would you consider making a bequest to Dying with Dignity NSW?

A bequest is a donation paid from your estate after you have died, in accordance with written instructions included in your Will. Bequests have formed a critical part of our revenue over many years, without which we would not be able to continue campaigning for assisted dying laws.

When making a Will, your first priority is to ensure that it reflects the way you want to look after your family and friends. Once you have done that, you may wish to make a bequest to **Dying** with **Dignity NSW ACN 002 545 235** to help us continue our important work. It is not payable until after your death, so it does not affect your assets or your cash flow during your lifetime.

You can either include the bequest when you write or update your Will, or simply add one as a codicil to your existing Will. If your circumstances change in the future, you can easily alter your Will. Following are some of the ways you could provide a bequest to Dying with Dignity NSW in your Will:

- **Specific bequest:** You can leave a specific dollar amount or specified assets.
- **Percentage of total estate:** You can leave a nominated portion of the total estate.
- **Residuary bequest:** The residue is whatever remains of your estate after you have made any specific provisions. You can leave all or a specified percentage of the residue.

You should always seek **professional advice** from a legal adviser to ensure your wishes are recorded in a legally binding way.

If you are considering making a bequest, we have provided some **suggested wording** for inclusion in your Will or codicil on our website at <u>dwdnsw.org.au/bequests/</u>

If you would like us to mail this to you or you would like to discuss a bequest with us please call our office on 02 9212 4782 or email dwd@dwdnsw.org.au



A bequest to Dying with Dignity NSW, no matter how small, is most welcome and appreciated. We hope that you will let us know if you leave a bequest to Dying with Dignity NSW.

## **PLEASE JOIN US**

If you are not already a financial member of Dying with Dignity NSW, you can join online at <u>dwdnsw.org.au</u>, or call our office on (02) 9212 4782 leaving your full name and postal address, so we can mail you the membership form.

Annual membership is \$50 (\$25 concession) or you can become a Life Member for \$500.



**EMAIL LIST** 

If you prefer not to join as a member, simply sign up to our emailing list. You can sign up online at <u>dwdnsw.org.au</u> or send us an email at dwd@dwdnsw.org.au

#### **THE IMPACT OF COVID-19**

## "It's robbed me of that comfort."

By the time we published our Autumn newsletter in March, the coronavirus had already impacted our organisation. Our AGM was postponed, our advocacy training days were put on hold and speaking opportunities virtually evaporated. However, it would have been difficult for us at that time to anticipate the significant impact COVID-19 restrictions would have on dying Australians trying to plan for a peaceful death with their loved ones.

Janet Cohen, who featured in our Summer newsletter, had planned to travel to a Swiss clinic to access voluntary assisted dying (VAD) when her suffering became intolerable. Despite having terminal lung cancer, Janet had been making the most of life enjoying music, art and regular bushwalks.

"Knowing that I had that option had a very strong effect on me. It allowed me to stop being worried, anxious and fearful about potentially dying a slow and agonising death and to get on with living," Janet said.

Unfortunately COVID-19 travel restrictions and global lockdowns have taken away that option.

"It's robbed me of that comfort," said Janet.

Janet's current situation highlights the inequity in access to voluntary assisted dying for terminally ill Australians. Since June last year Victorians have been able to access legal VAD and from June 2021 Western Australians will have the same compassionate, end of life option. But for dying individuals in the rest of Australia their choices are limited. Even without the travel restrictions, most cannot afford the cost of travelling to Switzerland estimated to be around \$20,000, or are simply too unwell to travel.

To add to their anxiety and distress, COVID-19 has also slowed political progress in states that were expected to debate assisted dying legislation in 2020.



Janet Cohen Photo by Rich Turley

Advocates in Queensland had hoped that the Labor Government would debate a VAD Bill before their election in October but instead Premier Annastacia Palaszczuk has referred the legislation to the state's Law Reform Commission for consideration. They won't have to report back to the Government until March 2021.

In South Australia the Parliamentary Inquiry into End of Life Choices was also delayed and in Tasmania, debate of their VAD Bill may be postponed until September.

Janet is particularly disappointed that assisted dying legislation has been put in the "too hard basket" in NSW following the controversial abortion law reform debate last year.

"But the evidence is clear. Australians who don't have access to legislation are dying drawn-out, painful deaths. They suffering unnecessarily. It's just not good enough."

#### **NEWS FROM NEW SOUTH WALES**

## Community advocacy training put on hold

Unfortunately, due to COVID-19 restrictions, our third community advocacy training session planned for the Southern Highlands had to be postponed. The ongoing pandemic and the vulnerability of many of our members means that face-to-face training days may still be some months away. However, rather than waiting, we have decided to adapt the training and deliver it via Zoom webinars. We still plan to provide localised sessions so that supporters in a particular area can get to know each other while learning more about the issue of VAD and ways that they can contribute to the campaign.

Access to a computer is a necessary component of the new training due the current circumstances but remember everyone can help lobby their local MP by writing a handwritten letter, even if you have written in the past.

Another way to help us build greater awareness and support in your local area would be to letterbox drop some of our VAD flyers. You can order the free flyers through our webstore or contact us on (02) 9212 4782.

#### Candidates who supported VAD in the Eden-Monaro by-election

In the lead up to the recent by-election for the federal seat of Eden-Monaro, DWDNSW sought the views of all 14 candidates to determine their position on Voluntary Assisted Dying (VAD) laws. Although VAD is primarily a state issue, we know that federal members of parliament can influence their state counterparts and it is a federal law that still prohibits the territories from considering VAD laws. We asked for a simple YES or NO answer to these questions:

**Question 1:** Do you, in principle, support the concept of voluntary assisted dying laws? That is, laws that would permit terminally ill people to ask for medical assistance to die, provided that they have decision-making capacity and are not subject to any coercion?

**Question 2:** Would you support the next Federal Bill that will restore the rights of the Territories to legislate to allow voluntary assisted dying?

It is always a challenge getting candidates to publicly commit to a position on what some see as a controversial issue. Despite several attempts there were three candidates who we had to leave as a question mark.

Labor's candidate Kristy McBain won the seat. We are confident that Kristy will support the next Bill that will restore the rights of the Territories to legislate to allow voluntary assisted dying.

Which candidates support voluntary assisted dying laws in the Eden-Monaro by-election?

Dying with Dignity

Candidate	
STADTMILLER, Matthew Shooters, Fishers and Farmers	?
JANSSON, James Science Party	$\checkmark$
BALDERSTONE, Michael Help End Marijuana Prohibition (HEMP) Party	1
HOLGATE, James	$\checkmark$
HICKS, Trevor The Nationals	?
McCRAE, Dean Liberal Democrats	1
ANGEL, Joy Sustainable Australia - Stop overdevelopment. Stop corruption.	1
McBAIN, Kristy	1
BOSI, Riccardo	?
PORTER, Karen	1
GRIFF, Cathy The Greens	1
STOREY, Narelle Christian Democratic Party (Fred Nile Group)	X
POTTER, Jason Australian Federation Party	X
KOTVOJS, Fiona	X

#### **NIA'S STORY**

#### "Victoria's VAD law has changed my life but will it change my death?"

On 3 March 2020, Nia Sims published this story to coincide with a special *Insight* program on SBS that investigated how Victoria's Voluntary Assisted Dying (VAD) law was working for patients and doctors. (The program can still be viewed via SBS On Demand - <u>https://www.sbs.com.au/</u> ondemand/video/1699323459507)

When Nia was just 23 years old she was diagnosed with a relatively rare auto-immune disease, scleroderma. Now in her mid 40's Nia's health has deteriorated significantly but it didn't stop her being a passionate advocate during Victoria's debate on the VAD Bill in 2017.



Nia Sims (far right) with fellow VAD advocates Jane Morris and Dr Rodney Syme AM in 2017.

#### **Nia's Story**

In the last six months, more than 360 Victorian doctors have qualified to provide assessment for Voluntary Assisted Dying (VAD) to people who are terminally ill, with less than six months to live. Doctors in Western Australia will soon have opportunity to do the same.

The Victorian VAD Review Board have published their first report of operations, indicating that 135 people began the assessment process between June and December 2019, with 52 having used the prescribed medication safely and effectively.

Access to VAD assessment in Victoria is precious to me. At 46, my body feels aged. I have scleroderma a disease of the body's connective tissue. Scleroderma means 'hard skin' and the most common symptom is a thickening and hardening of the skin, particularly of the hands and face. I may have less than five years to live, it could be 10, perhaps 20 years. Perhaps you can imagine what that might feel like? I spend about 16-18 hours each day in bed and perhaps three hours on my feet, short of breath, unable to walk far and with very limited, painful hand movement.

I fear dying from slow lung failure (being increasingly unable to breathe), starvation or slow heart failure.

Potential access to VAD has lifted from my aching shoulders my own fear of dying the way my dad did – in a slow, dopey agony. It allows me to connect in a more meaningful and caring way with my own fragile, crumbling body. It has freed me from planning future suicide and given me headspace to get on with living. Sure, I miss skiing, swimming, dancing, and I've not yet mastered the art of flirting while using a walking frame, but with existential and physical fears allayed, I've so much more to live for.

A few years after my diagnosis, when I was still working part-time as a registered nurse, I watched my 56 year old father die a horrific death from brain cancer – his slow decline to death took over nine months.

I watched him writhe in pain, drowning in lung secretions, in hospital in his final fortnight. He became more anxious after losing his ability to speak, and to swallow the tablespoons of lemonade. Thickened fluids were not offered.

He told us he was thirsty by opening his pasty, dry mouth (which was swabbed out thoroughly with oversized, mouthwash-wet cotton buds once or twice a shift). In the final days, with injection after injection of morphine, he remained mostly semiconscious, often flailing and agitated, despite what is called in palliative care "terminal sedation".

I knew my dad's values and beliefs. He would have thought the manner of his death shockingly torturous and undignified.

VAD is a profound freedom of choice for a government to allow its citizens.

I'm confident that I will be able to access VAD if/ when I am ready. I have spoken with my family, I have made an Advance Care Plan with the help of my doctor, and spoken openly about wanting the option of VAD assessment.

Victorian clinicians face the profound dilemma of being legally banned from raising the topic of assisted dying with patients. Intended to avoid any perception of coercion, though not addressed in the Vic Report, low levels of awareness in the public may be contributing to issues of equity of access. This is one of the areas ripe for a 'plan for research' that the Review board promises to undertake.

Western Australian politicians have seen fit to trust their doctors to judge when it is appropriate to provide patients with their full range of options for end of life care. This is the major difference between Victorian and Western Australian legislation.

The right to conscientious objection by clinicians is protected by the Victorian and WA laws. Conscientious objection of entire religious health organisations – a dominant presence in our hospital networks, aged care, and palliative care – is a more contentious legal provision, presenting a significant barrier to access to me and fellow Victorians.

With the help of the Government appointed VAD Care Navigator Service (for information and referral) I found a supportive GP who has agreed to assess me if/when I feel ready. I am still looking for a specialist in my disease who would act as the consulting (secondary) doctor. I'm uneasy about that – I'm told that so far, there are no rheumatologists who have trained.

Following the release of the Victorian Government VAD Review Board report, the Insight program on Tuesday March 3 brings together clinicians, consumers and activists who support and who oppose the existing legislation to discuss learnings from the first six months of operation in Victoria and implications for the future in Australia.

I'll continue the well-trodden path toward peace of mind about how to do my dying when the time comes. Watch this space.



#### **SPECIAL FEATURE**

#### The difference between terminal sedation and voluntary assisted dying

#### By Dr Peter Beahan and Dr Richard Lugg

#### Perth, Western Australia

Terminal Sedation (TS) and Voluntary Assisted Dying (VAD) are different approaches to the management of the approximately 5% of dying patients who experience overwhelming suffering. TS is also known as Palliative Sedation.

Opponents of VAD often say that such dying patients can be provided with TS. However, we believe that TS can be an inferior option to VAD for patients who are able to choose between them. The differences are summarised in the table opposite.

With TS, dying can take many days, and the time to death is unpredictable. The patient may linger in a semi-comatose state, dehydrated and deteriorating. This can be distressing to loved ones, who are not able to communicate with the dying person, or help in any meaningful way. With VAD, the person has capacity, and awareness, plus the ability to communicate and to initiate the process.

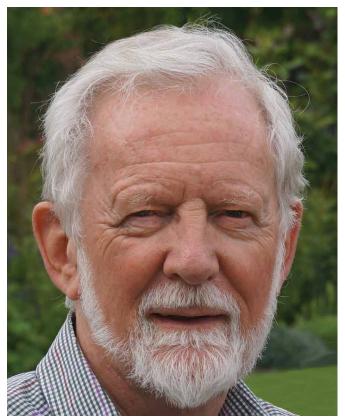
With TS, the decision to administer continuous sedative medication is often that of the doctor. The patient may not be able to indicate consent. With VAD, the dying person makes the decision while dignity and purpose are intact. This is both a rational and a mentally healthy choice, for those who take that option.

With TS, death can be a trial for all concerned. It can be remembered with guilt and horror. With VAD, the patient chooses the timing and the arrangements. Death is dignified and peaceful. It is often described as a 'good death' – a fitting end that complements and rounds off a person's life experiences and achievements.<sup>2</sup>

Terminal Sedation	Voluntary Assisted Dying
Dying can be prolonged and uncertain	Dying is quick and certain
The decision is most often made by the doctor	The decision is made by the patient
Death is often experienced by loved ones as undignified and harrowing	Death is experienced with reverence, thankfulness, and a sense of release
The time of death is indeterminate; patients sometimes die alone, to the distress of family	The time of death is chosen by the patient
Deep sedation may remove both consciousness and all semblance of personhood	Consciousness is preserved. Death is induced by fast acting and effective medication
Documentation may be cryptic, and clouded in secrecy	Documentation is regulated, transparent and subject to official scrutiny
Doctor accountability for process and outcome is not clearly defined	Doctor accountability is fully and clearly defined
Legal protections for the doctor (criminal homicide), and the patient (abuse) are minimal	The doctor and the patient are well protected by the law
Access depends on the doctor's attitude, including religious beliefs	Access is legally available, provided the patient is eligible
Neither capacity to consent, nor consent itself, is necessary, even from the family	Both capacity, and consent from the patient are required
No beneficial effect on bereavement	Beneficial effect on bereavement compared with death from natural causes <sup>1</sup>

With TS, sedative and analgesic medications are relied on to control the dying process and associated suffering. Even so, fluctuating levels of response mean that complete control of suffering cannot be guaranteed. With VAD, the dying process is brought to a conclusion by the administration of medication that is the same as, or similar to, that used for general anaesthesia. This can be self-administered by mouth, or given intravenously. The latter can be given by the doctor, or arranged for self-activated administration by the patient. Communication channels remain open up to the last minutes of life. The most important loved ones are usually present, or close by.

With TS, documentation may be incomplete and statistical information impossible to collect.



Dr Peter Beahan

There is no regulatory framework. With VAD, documentation is clear, frank and open to scrutiny.

Finally, there are some characteristics that TS and VAD have in common. In both, the primary aim of the doctor is the relief of suffering. In both, the patient is in the process of dying, and will inevitably die. In each case, the intent is the same, and the outcome (death) is the same.<sup>3</sup>

VAD will not be acceptable to some dying people, nor will it be available to some others. TS will continue to be a valuable intervention for such people, if they experience refractory suffering. It can be well accepted, where there is accountability, and good communication and care directed toward family members.<sup>4</sup>



Dr Richard Lugg

#### References

1. Swarte NB, van der Lee ML, van der Bom JG, vander Bout J, Heintz AP. *Effects of euthanasia on the bereaved family and friends: a cross sectional study. British Medical Journal 2003, 327,7408; 189* 

2. Reid T, *Reflections from a provider of medical assistance in dying. Can Fam Physician 2018, 64:640 repub. Medical Forum WA, Mar 2019* 

3. Lipuma SH Continuous sedation until death as physician-assisted suicide/euthanasia: a conceptual analysis J. Med Philios. 2013, 38:190-204

4. Bruinsma SM, The experiences of bereaved relatives with palliative sedation and other end-of-life care practices 2015, Thesis, Erasmus MC, University Medical Center Rotterdam

#### **NEWS FROM AROUND THE COUNTRY**

#### **Tasmania looks promising**

It is now very likely that independent MLC Mike Gaffney will table his *End-of-Life Choices* (Voluntary Assisted Dying) Bill 2020 in late August or early September. Despite the distraction caused by the coronavirus there have been a number of reports coming out of Tasmania over the past few months related to the upcoming VAD debate.

One young Tasmanian mother told local media that she would be prepared to move with her family to Victoria if the Tasmania Parliament fails to pass the upcoming VAD Bill. Louise Elliot does not want to die and she will do everything she can to stay alive, however, she knows she may reach a point when her cancer will cause unbearable suffering.

"I could not tolerate inflicting a significant amount of trauma on my young kids. I want to go to sleep peacefully," she told ABC radio.

Another woman with cancer has already planned to sell her home in Tasmania and move to Victoria because she wants the choice of VAD.

"When the time comes, I want to be able to choose to leave this world with dignity and not with my head in a bucket every day for the rest of my life," she said.

The vast majority of the media reports have been positive, including one on WIN News that reported that all 13 Labor members in the Tasmanian Parliament are supportive of VAD law reform. Labor MP David O'Byrne said that they will wait to see the final legislation but has indicated that there is philosophical support for greater end of life choices for Tasmanians within Labor.

There is also growing support on the Liberal side with Nick Street and the speaker, Sue Hickey making strong public statements in support of VAD. Sue Hickey recently shared a parliamentary petition created by two new advocates in the Tasmanian campaign. Natalie and Jacqui Gray set up a Facebook page called Your Choice Tas following the 'bad' death of their mother, Diane. As they said on their page in May:

"Your Choice Tas might appear to be two sisters and the legacy of their Mother fighting to legalise VAD in Tasmania... but we are far more than that! We are the Tasmanian community; every single one of you who have signed the petition, letterbox dropped or contacted your local MP. We are the many people who have contributed their time and advice on topics usually foreign to us. We are those that have donated toward producing flyers. We are the media who have rallied behind us to share our story. We are a large number of the politicians who are also actively supporting our fight."



Things are looking promising for Tasmania with the member for Franklin, David O'Byrne, helping to letter box drop some Your Choice TAS flyers and posting this image on his Facebook page saying "Doing some letterboxing for a good cause #yourchoice @ doingitfordisey @YourChoiceTAS"

# Disappointment in Queensland

Hopes of having an assisted dying law debated in Queensland before the state election were dashed when the Premier, Annastacia Palaszczuk, announced on 21 May that she would be referring the proposed laws which were recommended by the Queensland parliamentary inquiry to the *Queensland Law Reform Commission,* asking it to report back by March 2021.

Supporters of law reform had hoped that the Government would move quickly to put a VAD bill before parliament following the recommendations released in March. However, there are now genuine fears that if the LNP were to win the election on 31 October, Queenslanders could lose any chance of accessing legal VAD because the LNP has a policy opposing VAD law reform.

Following Palaszczuk's announcement, former premier Campbell Newman criticised the government saying that they had let down the thousands of people who had made their views in favour of VAD known during the inquiry. If the LNP does win government Mr Newman hopes they will still allow the legislation to proceed and support a conscience vote saying:

"This is about people, it's about their lives and their freedom to decide on how they live or die, when they're in a terrible situation, incurable illness."

One unexpected advocate has refused to give up hope. The Electrical Trade Unions of Queensland and NT (ETU) released an emotional video of former secretary, Peter Simpson who is dying of cancer. They have also created a special website urging politicians of all sides to support their campaign to bring the VAD legislation before Queensland parliament with urgency with a view to MPs voting on the proposed legislation before this term of parliament concludes.

Despite ETU's contribution and continuing advocacy by groups such as DWDQ, the Clem Jones Trust, Doctors for Assisted Dying Choice, Nurses Supporting Voluntary Assisted Dying and VALE, it appears very likely the VAD will become an election issue. Advocates across Queensland are now calling on voters to use their vote wisely in October to ensure enough MPs supporting VAD are elected. Watch this space!

# South Australians are still waiting

The Joint Committee on End of Life Choices (EOLC) has now completed the witness hearings and is taking into consideration both the written and the oral submissions when preparing their report. A date for the release of the final report is still unknown. Submissions can be found on the South Australian Parliament website under Committees – End of Life Choices.

### First anniversary of Victoria VAD laws

June 19 marked the first anniversary of Victoria's historic voluntary assisted dying (VAD) legislation. The exact number of people who have accessed the law in the first year will be reported in August, however, what can be said is that the VAD scheme appears to be functioning reasonably well, despite some logistical and bureaucratic issues.

According to media reports, approximately 400 people have made initial enquiries about accessing VAD but participating doctors believe there has been a surge of enquiries from terminally ill Victorians due to fears related to the coronavirus. According to Dr Cam McLaren at one point he saw three patients on the same day. "These are patients who were always going to go down that path anyway. Coronavirus has spurred them to take steps earlier to be organised and prepared," Dr McLaren said.



"What has happened is that a small number of people have had the huge relief of being provided with an option previously denied them." Dr Nick Carr

#### WHAT'S HAPPENING OVERSEAS

#### **USA - Massachusetts**

Prospects are looking favourable for another state in the US legalising voluntary assisted dying. In early June a Joint Committee on Public Health of the Massachusetts legislature approved a bill that would authorise medical aid in dying as an endof-life care option. This bill was first introduced in 2011 and it has taken its sponsors till now to get it to this stage. Recent polls show that 71% of citizens in Massachusetts support assisted dying.

The Massachusetts Medical Society (MMS) testified at the hearing in June 2019 before the Joint Committee, detailing its policy of "neutral engagement" on the practice of medical aid in dying "The MMS will support its members regarding clinical, ethical, and legal considerations of medical aid in dying, through education, advocacy, and/or the provision of other resources...". A 2017 internal survey of Massachusetts Medical Society members showed they backed the End of Life Options Act by a 2-1 margin, 62% support vs 28% opposed.

Medical aid in dying is legal in 10 US jurisdictions representing more than one-fifth (22%) of the nation's population, including nine states: Oregon, Washington, Montana (via a state Supreme Court ruling), Vermont, California, Colorado, Hawai'i, New Jersey, Maine, as well as Washington, DC.

#### Canada

Following our story in the last newsletter on the background to the Canadian law, we can now report progress towards a broader voluntary assisted dying regime for Canada (what they call medical assistance in dying – MAID) than the one that came into operation in 2016. A new bill entitled C-7 was due to be introduced into the parliament in July, however, the federal government has been granted an extension until mid-December due to the disruption caused by the COVID-19. It will repeal the provision that 'death is reasonably foreseeable', it will make clear that a person whose only medical condition is a mental illness will not be eligible for MAID and most significantly, it will allow MAID to be administered to a person no longer able to consent to it, provided they have indicated in advance that they would want MAID under certain conditions. This will allow MAID for people with dementia who drew up an advance care directive at a time when they still had decision-making capacity. However they would also have to have a life-limiting illness.

Justin Trudeau's Liberal government undertook a public consultation leading up to this bill with 300,000 online submissions and four out of five respondents – 236,000 in all – said they supported people with dementia being able to lawfully request MAID before they lost their decision-making capacity. However, the sponsor of the bill said at this time it was not possible to extend MAID to people whose only illness is one that causes dementia.

At the same time as C-7 is proceeding (under a court-imposed deadline) the government will conduct a parliamentary review of how the MAID regime has been operating and in the course of that review, it is very likely that provisions that Canadians are calling for, such as extending MAID to those with mental illness, those with dementia and minors will be looked at.

The other significant change in the C-7 bill is the dropping of the requirement for patients to have to give consent a second time just before the procedure takes place. The sponsor of the bill calls this change the 'Audrey Parker amendment' after its namesake who elected for a medically assisted death earlier than she wanted out of fear she would lose capacity for the second consent before the procedure had happened. Parker had breast cancer which had spread to her bones and brain and she was afraid she would lose her stable mind and be unable to consent at the appropriate time. It is chastening for us in Australia to contrast the way Canada has moved towards voluntary assisted dying with our own snail-like progress. Canada's national system of MAID has happened because courts ordered the government to introduce it. This is a result of their interpretation of Canada's Bill of Rights, which, under section 7 of the Charter, guarantees the right to life, liberty and security of the person. We could only wish we had such a Bill of Rights.

#### **New Zealand**

As we reported in our Summer newsletter, New Zealand passed a voluntary assisted dying bill in November 2019. Known as the End of Life Choices Bill, it is not yet law. The next stage is a referendum to be held at the same time as New Zealand's next election, still scheduled for September this year in spite of COVID-19. Polls consistently show that more than 70% of New Zealanders support the bill and had been thought that Maori might be opposed for cultural reasons but a recent survey found that 72% of Maori will vote in favour at the referendum. It was very pleasing to see that the Prime Minister Jacinda Ardern is such a strong supporter of VAD. In contrast, leaders of the opposition National Party have been vocal in their opposition to VAD.

In a small setback Hospice New Zealand (NZ), which is the peak body of the Hospice Movement, applied to the New Zealand High Court in May for a ruling about whether it can conscientiously object to assisted dying and whether funding would be denied to it if it did opt out. A Hospice NZ spokesman said the application was necessary in order for it to advise its members ahead of the referendum. In fact the Bill does give individual doctors the ability to opt out of the process but they must advise the patient about how to obtain the name of a doctor who will offer VAD to that patient. It is less clear what happens if a whole institution refuses to participate in assisted dying. The Court released its finding in mid-June. The judge rather surprisingly said that even though the Bill will make it an offence for a doctor to refuse to provide VAD, it does not require hospices or other organisations to offer them. Happily, Hospice NZ does not control

individual hospices. They are able to make their own decisions about participation. We will watching these developments with interest because what happens in close jurisdictions such as New Zealand and the Australian states which have already legalised VAD will influence how NSW politicians think about the issue.

Because voting is not compulsory in New Zealand it is critical that supporters of VAD vote YES in the referendum. Huge numbers of Kiwis are living in Australia and we are encouraging them to register as overseas voters so they can support the End of Life Choices Act in the referendum.



### **United Kingdom**

On July 15 the All Party Parliamentary Group on Choice at the End of Life will meet to hear harrowing personal stories and overseas experts on voluntary assisted dying including our Victorian Attorney General and former Health Minister, Jill Hennessy MP.

One of the testimonies will be by Joy Munns, whose 81-year-old mother faced going to prison for murder after she helped her terminally ill husband take his own life.

"My mum and dad were together for 60 years and she would have done anything for him - including helping him to die peacefully and without pain. But her actions, motivated wholly by love, landed her in cell for 30 hours and then in the dock on trial for murder," said Ms Munns.

She believes an assisted dying law would have allowed her father to have a peaceful and dignified death, and saved her mother the trauma of a criminal investigation and murder trial. Ms Munns joins other UK advocates calling for an inquiry on assisted dying.

#### **REGIONAL AND OTHER GROUPS**

#### **Mid North Coast**

Due to the continuing COVID-19 restrictions our group has not met during the past three months. With the uncertainty prevailing at the present time, the demographic of our group and with the winter season upon us it is highly unlikely that we will meet again within the next three months.

The organising team has remained in 'idle mode' and is keeping abreast of current issues to enable an appropriate response as and when required.

Group members and supporters will continue to be informed of current issues through the DWD NSW newsletters and email updates.

Should Group Members/Supporters require any further 'local' information, please feel free to contact us.

#### Paul Newman - Convenor

Email: pmq@dwdnsw.org.au Phone: 02 6582 0525

#### **Central Coast**

Since our February meeting (reported in the last newsletter), the Central Coast Group has, unfortunately, largely been in abeyance because of the coronavirus. We cancelled our planned May meeting and, at this stage, it is unlikely that our August meeting can go ahead.

Even if gatherings of 40-50 people were allowed by then, the need to still follow social distancing in the room would mean reduced numbers of people – possibly only 25-30 - able to attend. Not only would this be unfair on our planned speaker, it would be financially unviable, as we rely on donations from attendees to meet most of the meeting room cost.

Therefore, we have had to postpone our invited speakers for both meetings: Stuart Carter on the Funeral Industry and Michelle English, of the Newcastle Branch of the NSW Trustee & Guardian, on Wills, Powers of Attorney and Enduring Guardianships. We hope to have Michelle speak at a meeting in the near future.

Hopefully, our 27 November meeting, with Stuart Carter speaking, will go ahead as planned. This final meeting for the year is always a bit special, as it includes a Christmassy morning tea. We hope to see a large gathering of members and supporters along, to the usual place – Meeting Room 3 (opposite Library desk), The Hive, Erina Fair.

Wishing everyone continued good health.

**Beverley Symons,** Coordinator, DWD NSW, Central Coast Group Email: centralcoast@dwdnsw.org.au

#### News from Christians Supporting Choice for Voluntary Assisted Dying

With the lack of VAD activity in Parliament in NSW, and deferral of Queensland legislation to a Law Reform Commission, my main activity has been to offer help in Tasmania as the Mike Gaffney Draft VAD Bill opens for public consultation. The Advocate in Tasmania had an article prompted by an ACL (Australian Christian Lobby) Media Release. Mr Brohier, for the ACL, claimed the draft Bill was "hopeless" and that it "promotes hopelessness and fear" and was "promoting a sense of despair instead of purpose and endurance".

I was given the opportunity to have input, and the Advocate link was "Christian groups clash over euthanasia". The article included:

Christians Supporting Choice for Voluntary Assisted Dying spokesman Ian Wood said it was deplorable the ACL was fear-mongering on the bill with its use of the terms "hopeless", "hopelessness" and "suicide".

"The ACL speaks for only a small minority of Christians," Mr Wood said.

"We are Christians who believe that, as a demonstration of love and compassion, those with a terminal illness should have the option of a pain-free, peaceful and dignified death with legal voluntary euthanasia or VAD."

*Mr* Wood said those who opposed the concept of VAD were free to make their choice not to request assistance.

"It may seem paradoxical but there is considerable evidence that those who request and are approved access to an assisted death frequently live longer and have a better end quality of life than those who do not request assistance," he said.

"The choice removes the toxic fear of how that person might die and puts them back in control."

I have also been following with interest the New Zealand campaign in the lead up to the vote in a Referendum in September. A Yes vote will see their End of Life Choice Act take effect. A "Yes for Compassion" group with some very high profile members and speakers has been formed to coordinate the Yes Campaign.

**Ian Wood,** Spokesperson, Christians Supporting Choice for Voluntary Assisted Dying.

New members very welcome. It's free! Join us today at <u>https://christiansforvad.org.au/sign-up/</u>

## Does your doctor respect your right to choose?

If possible, you should all plan for a good death by having a valid and up-to-date Will, signing an Advance Care Directive, appointing an Enduring Guardian and making sure our health practitioners and family members know what we want should we become terminally ill. One of the most important things you can do if we want the choice to end suffering at the end of life, is to find a doctor who supports Voluntary Assisted Dying (VAD).

Even though NSW is yet to pass voluntary assisted dying legislation, understanding your own doctor's view on VAD could not only provide peace of mind, it could also help NSW achieve a VAD law sooner rather than later.

Next time you see your GP, a specialist, a nurse or any other allied health worker, ask them if they would be willing to add their name (publicly or anonymously) to a list of health professionals who support VAD on a national website. They can add their name to the list on the HPAD Choice website at <u>www.hpadchoice.org.au</u>



HPAD Choice supports greater patient choice at the end of life and the introduction of voluntary assisted dying (VAD) laws across Australia.

### **MAKING A DONATION**

## We are totally reliant on membership fees, donations and bequests to operate.

Donation	is can be ma	de via ou	ur websit	e –									
	For more information					First Name:							
	Visit www	.dwdns	w.org.au			_							
	ely, you can r ment options		onation vi	a our		S	urnam	ie:					
DWD NS PO BOX		-	orm to:			A	ddress	6:					
	the complete is at dwd@dv			the									
Payment Please se	Details elect ONE pa	lyment o	ption bel	ow:									
I will deposit the amount into the Westpac bank account: Dying with Dignity NSW BSB: 032 249				P	Phone:								
Account: 160 719				E	Email:								
	lose a cheque VD NSW)	e or mone	ey order (p	ayable		_							
	e charge my er details belo		urd or Visa	Card									
Card h	older name:												
Card n	umber												
Expiry	Date		CCV nun	nber – la	ast 3	digits	on bac	ck of c	ard				

Card holders signature:

Total amount to be charged to your card