

Dying With Dignity Victoria

Respect the right to choose est. 1974

NEW LOOK DWDV 2019

BY HUGH SARJEANT, DWDV PRESIDENT

Although the Voluntary Assisted Dying Act was passed in 2017, we were still focused on campaigning in the 2018 Victorian state election, in promoting the (re)election of candidates supporting voluntary assisted dying. We feared that if there was a sufficient swing away from these candidates, the newly enacted voluntary assisted dying legislation would be under threat of repeal or adverse regulation.

With no change of government from the November 2018 state election, which ensured the security of the legislation, it was time to focus on matters other than campaigning.

The DWDV board realised that with the implementation of VAD on 19 June this year, the need for education of the community would increase. We had to educate the community not only about Advance Care Directives and appointing a Medical Treatment Decision Maker, but now also about voluntary assisted dying - who is eligible and what are the processes involved. This need was confirmed by a marked increase in requests from community-based organisations for information sessions, as well as strong registrations for our in-house presentations, mostly held at Kew Library.

We also had a financial issue to address. We had run down funds in the two recent campaigns, as our priority was to first get legislation up, and then to defend the process. But the effect was that we could not maintain current staff levels, and still budget for a viable future. With great reluctance we reduced permanent staff to one part-time position. And we sought other services in recognition of our new needs.

What was required for the future was greater community engagement and outreach requiring personnel with appropriate communication skills: writing, website, newsletter, Facebook and presentations.

New mailing address:
PO Box 743 Kew VIC 3101

New phone number:
0491 718 632

To complement our Administration Manager Natalie, we have appointed as contractors Sue James and Sabrina Rudd.

Sue James - has thoroughly revamped our website and prepared this newsletter; also Sue will be providing presentations on end-of-life choices, starting 2 September.



Sabrina Rudd - is a very experienced Facebook user, who has been enhancing our Facebook presence and responsiveness for the last few months; Sabrina too will be providing presentations on end-of-life choices from early next year.



It was also clear that maintaining an office was a luxury beyond what we needed. We were having very little face-to-face contact with members, and so a considerable saving would be made if our support staff/contractors were willing to work from home.

Accordingly, we are moving to a virtual/distributed office, so closed the Mitcham office at the end of August.

"What is required for the future is greater community engagement and outreach"

DWDV DONATIONS NOW TAX DEDUCTIBLE



Dying With Dignity Victoria has now had its application for Deductible Gift Recipient (DGR) status approved by the Australian Charities and Not-for-profits Commission (ACNC).

This means that all donations to DWDV for more than \$2 are now tax deductible. This decision is retroactive from 22 February 2019, which affects the last financial year. All donations since that date can be claimed as tax deductions.

[Please Donate](#)

NEW BOARD MEMBER

DR PATRICK MCCARTHY

We are delighted to welcome Dr Patrick McCarthy as a member of the DWDV Board.

Dr McCarthy had always supported the aims of DWDV, but hadn't appreciated all of the implications until more recently. He has been deeply moved by the strength of public support and many people have spoken to him with great passion about the very painful deaths of loved ones. This experience has strengthened his resolve to make a contribution.

He is keen to support our ongoing work with community outreach and education - assisting people with end of life choices and access to Voluntary Assisted Dying. He is particularly keen to assist in preparing for the review in 4 years' time, through understanding the legislation in practice with a focus on improvement

Dr McCarthy has 35 years' experience of improving fundamental systems and cultures in large commercial, SME and not for profit organisations. His career has spanned senior executive roles both in Australia and overseas, adjunct professorial appointments at RMIT University and Swinburne University of Technology and appointments to a range of different Advisory Boards. He was awarded his PhD in 2007 and has produced many research papers and articles.



He is highly experienced in organisation-wide projects driving new ways of thinking and managing, including managing the 'people aspects' of the change. In 2003, he received the Diversity@Work award for "outstanding innovation by an individual- leadership in promoting workforce diversity in relation to the employment of mature age workers".

The extensive skills and experience Dr McCarthy brings to our Board will be a wonderful asset, and we look forward to his valuable contribution in the leadership and management of DWDV.

WANT TO HELP OUT?

CONTACT us on
0491 718 632 or email
office@dwdv.org.au

Many of our wonderful DWDV members have asked how they can help. Here are a few ideas:

- **at our workshops - help with setting up and taking down of tables and chairs**
- **participate in discussions on our facebook page**
- **we also need people with skills in writing, editing and workshop presenting**

VOLUNTARY ASSISTED DYING NOW AVAILABLE IN VICTORIA

On 19 June 2019, Victoria's Voluntary Assisted Dying Act 2017 came into force. The government has gone to great lengths to fully prepare for its introduction, since the law was passed 18 months earlier, in late November 2017.

This landmark legislation now allows a suffering person meeting strict eligibility criteria to seek medical assistance to die, to end their suffering. It is a complement to palliative care, rather than an alternative.

While the law as enacted is not all that DWDV wanted, it is still a huge, welcome step forward in the campaign for self-determination for people suffering near their end of life.

We would have much preferred to have no reference to the requirement for *death expected in less than 6 months* (12 months in the case of neurodegenerative disorders), which is now part of the legislation. Some overseas jurisdictions have a softer requirement in this respect, such as Canada, where the criterion is *death is foreseeable*. But in DWDV's view, the only requirement should be that there is *unbearable suffering that cannot be relieved in a manner acceptable to the person*.



Probably this is the biggest issue we have with the current legislation, which will act to severely limit people's access to voluntary assisted dying.

Please see the article on our analysis of the implementation of voluntary assisted dying on page five.

"While the law as enacted is not all that DWDV wanted, it is still a huge, welcome step forward in the campaign for self-determination for people suffering near their end of life."

PLANNING FOR VOLUNTARY ASSISTED DYING

Both participation in, and access to, voluntary assisted dying requires preparation and planning.

Voluntary assisted dying is one end-of-life option among many and people should take time to consider all their options. Health services and patients need to allow time to plan and prepare and it is important to have conversations about expected timeframes, and what is possible and appropriate at the start of the process.

For medical practitioners, this includes allowing sufficient time to sign up for and complete the Voluntary Assisted Dying Training and to register for the Voluntary Assisted Dying Portal.

It may also take time to identify appropriate medical practitioners to participate in and support the request and assessment process.

For people wanting to access voluntary assisted dying, this means they should read and understand the community and consumer information available on the Department of Health and Human Services website.

This includes information about having appropriate supporting documentation, such as proof of citizenship and proof of residency, at the time eligibility assessments are undertaken.

[DHHS, VAD Taskforce Implementation News]

NOW, WHERE DID I PUT THAT ...?

BY DR NICK CARR
DWDV BOARD MEMBER



It's been stated many times how Victoria's Voluntary Assisted Dying (VAD) laws are the most restrictive of any VAD laws worldwide. Three of the more reasonable sounding eligibility criteria are about demographics. These are:

- Over the age of 18
- An Australian citizen
- Normally resident in Victoria for at least the last 12 months

It's not enough just to accept someone's word about these matters; the coordinating doctor is required to upload documentary evidence to support each criterion. Again, this sounds reasonable, but after talking to a few people exploring the VAD option, some issues have arisen.

Perhaps not surprisingly, sick people near the end of their lives do not have as their prime focus good management of paperwork. As one man said to me, "I'm going to be dead before the end of the year, why would I keep my old utility bills? I've thrown them all out." Even if good at hanging on to paperwork, elderly people may not have, for example, a current driver's licence or passport.

One woman with advanced cancer has lived here since 1961. She has an Australian pension and is registered to vote BUT she was actually born in the UK and despite living here for over 55 years, has never become an Australian resident.

The prospect of having to find the relevant documents, fill in all the forms and wait weeks or months to become a citizen is overwhelming for her.

Another man, also with advanced cancer, lives in a nursing home and has no access to his documents. Family members cannot find his birth certificate, nor can they find any of the supporting documents needed to apply for a replacement certificate. He was born in this country, but at the moment cannot prove this.

We have said before in this newsletter that those who think they might want to access VAD should start preparation early. Previously we have said this because it may take time for their doctor to undertake the training, or to find other appropriate help. With my recent experience, I would now add, get your paperwork sorted out well in advance. Documents that are acceptable as proof of demographic eligibility are detailed on the VAD portal, and are listed below:

Aged 18 years or older

- Medical records
- Birth certificate
- Victorian driver's licence

An Australian citizen or permanent resident

- Australian birth certificate for people born before 20 August 1986
- Passport establishing Australian citizenship
- Permanent resident visa
- Permanent resident Visa Grant Number

A Victorian resident for 12 months or more

- Victorian driver's licence or vehicle registration
- Registration on the Victorian electoral roll
- Patient's medical record (showing their Victorian residential address)
- Lease document and utility bills

**"Get your
paperwork sorted
out well in
advance."**

THE VICTORIAN EXPERIENCE TO DATE: SOME IMPLEMENTATION ISSUES

On 19 June 2019 the legislation passed in November 2017 was declared implemented. Seen as better than nothing, but also overly restrictive – disallowing too many reasonable claims for assistance in order to guard against undesirable but unlikely outcomes.

The Victorian progression (18 months) since the enactment of legislation is seen as successful, in comparison with e.g. the Canadian experience where the legislation was in force immediately it was passed.

However:

- Doctors are prevented from raising the topic of Assisted Dying with their clients. Some doctors consider this puts them in breach of their duty of care, because it deprives patients of fully informed consent for other treatments, if they are not offered all possible alternative options available to them;
- The requirements for doctors seem burdensome: needing two, but under the assumption that one must be a ‘specialist’ would appear as a doctrine of perfection but often hard to implement. To find a specialist, and one who is prepared to assist, seems to be difficult;
- A ‘Navigation’ service has been developed, but appears to be insufficiently resourced. For example, there is at present no government-sponsored system to provide information to identify doctors who will assist someone whose own doctor will not assist;
- Section 474.29 of the Criminal Code (Using a Carriage service) has resulted in limitations to the provision of advice, as it makes it an offence to transmit that advice through emails, text messages or other electronic media;
- Some politicians seem insufficiently informed, on matters that their constituents might raise with them;
- Whilst there has been 18 months of well-regarded preparation, it would seem that many doctors are left anxious about involvement, being unsure of the requirements;



- The system relies on two doctors being able to agree that (in general) death will occur within six months. According to Dr Danielle Ko, Quality and Safety Lead, Austin Health, and Member of the Voluntary Assisted Dying Review Board, doctors’ skills are insufficient to make reliable prognoses (address to a seminar at the Law Institute of Victoria, 18 June 2019). It might be better to express the requirement as being that death is reasonably foreseeable, or some such less precise term.

From the DWDV submission into the South Australian Joint Committee of Inquiry into End of Life Choices.

**Please let us know
if you are
considering going
through the VAD
process.**

IT WAS A BEAUTIFUL, POSITIVE EXPERIENCE

This is how her daughters described the death of Kerry Robertson, 61, who was the first person to receive a permit through Victoria's Voluntary Assisted Dying Act and also the first to see the process through to its end.

Daughters Jacqui Hicks and Nicole Robertson were with her at the end. Not only did they say it was a beautiful, positive experience for their mother, but that "It was the empowered death that she wanted."

Ms Robertson, from Bendigo, was diagnosed with breast cancer in 2010. Despite treatment, the cancer metastasized into her bones, lungs and brain.

In March this year, when the disease had also spread to her liver and the side effects from the chemo were no longer manageable, she made the decision to stop all treatment.

In May she went into a hospice, as her symptoms had rapidly worsened and she was suffering severe pain, nausea and vomiting. By June, when she moved into a nursing home, she had also lost most of her vision and needed assistance with all daily living tasks.

Her decision to access Voluntary Assisted Dying was made some time before the legislation was implemented. On the day it came into force, on 19 June, she spoke to her specialist and submitted her initial request to access the medication.

She chose to take this on the same day it was hand-delivered from the state-wide pharmacy.



Jacqui Hicks (left), Kerry Robertson, and Nicole Robertson (right)
(Image credit: Go Gentle Australia)



Kerry Robertson
(Image credit: Go Gentle Australia)

The full process, from her initial request to her death, took 26 days to complete and her daughters said it all went very smoothly.

Daughter Nicole said her mother had been "ready to go": "Her body was failing her and she was in incredible pain. She'd been in pain for a long time. Palliative care did their job as well as they could. But it had been a long battle. She was tired, the pain was intolerable and there was no quality of life left for her".

"We were there with her; her favourite music was playing in the background and she was surrounded by love. She left this world with courage and grace, knowing how much she is loved."

The sisters also said their mother's death had reinforced their belief that anyone who was terminally ill and in intolerable pain deserved the choice of a voluntary assisted death. "It is the most compassionate, dignified and logical option for those suffering in the end stages of life," Nicole said.

Go Gentle Australia's director Andrew Denton said the story demonstrated how well the law had been designed and implemented.

"The eligibility criteria were met, the safeguards were worked through, and Kerry Robertson and her family were offered the compassionate death Kerry wanted," Mr Denton said.

"Importantly, too, access to the process was not an issue, even though the family was from regional Victoria. It is a testament to the dedication and compassion of everyone involved."

IN OTHER NEWS...

Uniting Church in Victoria permits VAD in its facilities

In July the 14th Synod Meeting of the Synod of Victoria and Tasmania gave permission to the relevant UCA institutions and associated hospital group within Victoria, to make VAD allowable for their patients, clients and residents, under the specific conditions of the legislation.



VAD Printed Materials Available

Printable materials about VAD are available from DHHS via website download or email request.

Nurse, GP positions on VAD are game changing

The Australian Nursing Federation WA released the results of a survey of its membership and said in a statement that “*Terminally ill patients who are suffering terribly should have the legal right to ask for medical help to end their life – with the protections and safeguards of Voluntary Assisted Dying (VAD) laws*”

WA Parliament Begins Assisted Dying Debate

Voluntary Assisted Dying Bill 2019 has been tabled in the Western Australian Parliament. Debate commenced on 28 August.

The way we die will be considered unthinkable 50 years from now

This is an excellent article by Haider Warraich, an American cardiologist at Duke University Medical Center and the author of *Modern Death: How Medicine Changed the End of Life*. He argues that in 50 years' time, we will look back and conclude that medicine was sorely lacking in relation to how we handle death.

What we didn't expect in my mom's journey with assisted dying

From Dying with Dignity Canada comes this story about one woman's experience of her mother's journey with assisted dying and some of the challenges her family faced.

Oregon removes assisted suicide wait for certain patients

In Oregon, USA, legislation allowing certain terminally ill patients to have quicker access to life-ending medications has been signed into law.

What Happens When We Die?

An excellent article that looks at the process of dying, how you can prepare for it and how you should be with someone who is nearing the end of life.

For more information and to read these articles in full, go to
<https://www.dwdv.org.au/news/category/key-developments-shortlist>

WORKSHOPS

Have you started your Advance Care Planning conversation?
Do your family and friends know your future wishes?

DWDV presentations explain how to complete your Advance Care Directive, and how to appoint your Medical Treatment Decision Maker.

YOUR LIFE, YOUR CHOICE

Learn how to make sure your wishes are respected and enforced

Book via the DWDV website www.dwdv.org.au

- Mon 7 October, 10am at Kew Library

Members \$50 (\$25 conc.), non-members \$75 (\$50 conc.)



ANNUAL GENERAL MEETING

Saturday 16 November

2:00 pm

Unitarian Church
110 Grey Street
East Melbourne

We hold regular presentations on Advance Care Planning and Voluntary Assisted Dying.
Do you know of any group that would like us to deliver a presentation for them?
If so, please let us know!



PRESIDENT

Hugh Sarjeant



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Lesley Vick



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TREASURER

Mark Newstead

AND THE BOARD...

Dr Nick Carr, Dr Peter Churven, John Hont, Prof. Carmel McNaught, Dr Patrick McCarthy

AN IMPORTANT REQUEST!

Next time you see your GP ask the following question: "If I were eligible under the Voluntary Assisted Dying Act, would you support me if I wanted to use the process?"

If the answer is yes, ask "Have you already done the VAD training? If not do you intend to do it soon?"

Explain to your GP that DWDV is compiling a highly confidential list of supportive GPs, that can be accessed **ONLY** by Dr Rodney Syme. If the GP is supportive, ask whether the GP agrees with their name being added to this list.

Then please let us know by calling our office on 0491 718 632 or emailing us at office@dwdv.org.au

Help us to help you and others.

