

Dying With Dignity Victoria

Respect the right to choose est. 1974

NATIONAL DYING WITH DIGNITY CONFERENCE 2020

Following a suggestion from WA late December that there be a conference of the Dying With Dignity and Voluntary Euthanasia societies of Australia, we offered to host. The stated aim was to pool experience on what has worked in campaigning, see how those who have legislation might help those who do not, and improve communication between us all. The conference was not open to the public. Such a conference had not been held for ten years.

As the only state with experience of VAD in practice, we could offer useful information on both the experience and problems since implementation. People from other jurisdictions were able to provide useful insights from their campaigning experiences.

Various constraints on the availability of people meant we were set a rather tight timetable to have the conference program in place by the weekend of 7-8 March. The whole planning process exemplified the problem of seeking a like-mind from organisations separated by distance, experience, resources and perhaps outlook. We were fortunate to get representatives from each state and territory except the ACT, though we did receive written submissions from there. Various State and Territory representatives were active in making presentations, chairing sessions, and/or contributing to the sharing of information.

We were also fortunate to get attendance from other organisations and individuals. Rodney

Syme opened the conference, and was active throughout. Go Gentle Australia (GGA) founder Andrew Denton gave an excellent address; and Kiki Paul in conjunction with others provided a useful presentation on campaigning. Doctors for Assisted Dying Choice and representatives of Christians Supporting Choice for VAD also attended and provided useful input. We also heard from Simon Ramsay (former Liberal politician), and Paul Price who was active in the Victorian campaign.

The feedback has been complimentary of the conference as a whole. It was difficult to provide for all suggestions, and to accommodate presentations within the time available.

However, it certainly allowed us all to meet each other; the information provided was insightful; and it seems likely that the contacts established will be maintained. Our website will show some photos and a video by secretary Meredith Doig, and we will maintain records of conference materials and contacts into the future.



THE CORONAVIRUS AND DWDV ACTIVITIES



We have long made presentations to the public on matters related to end-of-life choices.

These have changed since the passage of VAD legislation, and changed again following implementation of the Voluntary Assisted Dying Act. Indeed, the content seems to change with every presentation, as new issues arise, and questions from the audience provoke clarification.

As mentioned in our last newsletter, we have sought to expand our coverage of Victoria by offering short and full-length presentations to interest groups and local government, and a start has been made on that exercise.

However, on the advice of our doctors on the Board in relation to the Covid-19 problem, we have given notice that we will not offer such presentations for now. This decision has been overtaken now by the more recent prohibition of public gatherings.

We will resume when it seems productive to do so.

We have been pleased to have so many of our members offer to serve as Witnesses and/or Contact Persons. Witnesses are needed to complete voluntary assisted dying application forms; Contact Persons are needed as part of the last stage before provision of medication for VAD, or for its disposal later.

Two matters have changed for our provision of this service:

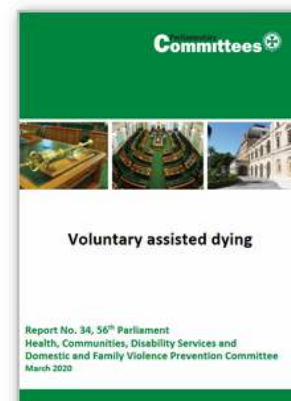
- Members may want to consider any risks to themselves, from being in contact with outsiders;
- Whilst this service commenced following a perception of need from the VAD Navigators, the word seems to have got out into the community that we offer this service as a matter of course, not just when no other suitable people are available. We will be watching how this develops, and respond as necessary.

QLD PARLIAMENTARY COMMITTEE REPORT ON VOLUNTARY ASSISTED DYING

The 56th Parliament Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee in Queensland, has released reports on its inquiry into aged care, end-of-life and palliative care and voluntary assisted dying.

Thousands of people participated in the inquiry, which was extensive and the committee heard from both those who supported VAD and those who opposed it.

The report reflects the views of the majority of Queenslanders - and the majority of the committee voted to recommend a legislative scheme for voluntary assisted dying in Queensland.



SBS INSIGHT PROGRAM: VOLUNTARY ASSISTED DYING



On 3 March 2020, SBS's program "Insight", hosted by Jenny Brockie, focused on the topic of Voluntary Assisted Dying.

DWDV Board Members, Dr Nick Carr and Dr Cam McLaren, were amongst the selected few asked to discuss their thoughts on VAD and related experiences since the implementation of VAD in Victoria.

They talked passionately and frankly about their innate desire to help their patients and other individuals achieve a dignified death. They emphasised the importance of being able to provide care for their patient right up to their journey's end. It was evident, as they reflected on particular instances, that the effects of their VAD involvement were not solely confined to their professional parameters but encroached into their everyday personal lives. They spoke not only with deep respect for their patients and families but also for the process of VAD itself.

Associate Professor Mark Yates (Geriatric Medicine) and Associate Professor Natasha Michael (Cabrini Health, Palliative Care Physician) represented those opposed to VAD. Much to the chagrin of many other participants, who recounted experiences of having witnessed extreme suffering at the end of life, they sought to argue that all end-of-life physical pain is able to be successfully ameliorated by palliative care.

From the ensuing discussion it became evident that a fundamental difference in the views of medical practitioners arises from a physician's interpretation of the medical 'social contract'. It was stated from an anti-VAD perspective that *"Our social contract is that we should never intend that (our patients) be killed by our action"* - a reference dating back to the time of Hippocrates.

A more contemporary explanation was offered by Dr Nick Carr, *"My social contract with my patients is to respect their wishes and their autonomy and help them live their lives the best way they can, which includes helping them end their lives the best way they can. Not my choice, their choice"*.

Despite the personal stories recounted by those who had witnessed extreme suffering in death of loved ones, there were also accounts from relatives who had been privy to 'beautiful' deaths.

Such deaths included one that resulted from Victoria's newly implemented VAD and another by the loved ones of a woman whose dignified death necessitated travel to Switzerland.

The sufferer of a terminal disease provided testimony regarding inefficiencies within Victoria's system and her extreme frustration resulting from the inequity of access for some.

It was indeed extremely 'insightful' viewing and highlighted the need for many more similar discussions to take place to further inform the public about this most critical issue.

Watch the full Insight Program on SBS On Demand:

<https://www.sbs.com.au/ondemand/video/1699323459507/voluntary-assisted-dying>

VOLUNTARY ASSISTED DYING REVIEW BOARD- SECOND REPORT

The Voluntary Assisted Dying Review Board released its second half-yearly report in February. This reported on the period since the Voluntary Assisted Dying Act came into operation on 19 June 2019, to 31 December 2019.

It is pleasing to note that the Act has been functioning without abuse or any evidence of coercion. However, the report does indicate two very important issues:

- That it takes time and planning to complete the process; and
- That a lack of documentation of citizenship or a permanent residency visa can stymie the process for people who have actually been residents in Victoria for many years.

A most interesting finding in the report was that while the government had anticipated only about 12 people accessing voluntary assisted dying in the first year, already in the first six months of operation, 136 people commenced the assessment process; 52 resulted in confirmed deaths. This represented 0.2% of all deaths in Victoria during that period, which is still a very small proportion.

DWDV would have liked to see much more data being made available in the report. Section 117 of the VAD Act requires the Board to record, retain statistical information on

- (2) (a) the disease or medical condition of the person that met the requirements of the eligibility criteria;
- (2) (b) the age of the person at the date of the person's death; and
- (3) the Board must make the statistical information recorded and retained publicly available ... on an internet site maintained by the Board.



The above-specified information was not made public in the report nor was a reference provided to an internet site containing the information.

There were some other significant data gaps in the report:

- 136 people were eligible at a first assessment, but only 102 had a consulting assessment. There is no detail as to what occurred to the missing 34.
- Of the 81 approved permits, 19 were withdrawn (an astonishing 23%) with no clear reasons given.
- 365 doctors had registered for training at 31/12/19, but only 134 had registered for assistance. There is no indication as to how many are GPs or specialists, nor the number in any particular speciality. This is important information in view of the fact that the government has decided that one of the assessing doctors must be a 'specialist', although no definition is included in the Act.

DWDV looks forward to a more comprehensive, more detailed report, due in August.

COMMONWEALTH LAW IS AN IMPEDIMENT TO VAD

The Voluntary Assisted Dying Review Board provided the following statement in its 19 February 2020 report.

The Board is concerned about the impact of sections 474.29A and 474.29B of the Commonwealth Criminal Code 1995 as amended by the Criminal Code Amendment (Suicide Related Material Offences) Act 2005 on voluntary assisted dying.

This commonwealth law means that it is an offence to use a carriage service (such as telephone or telehealth) for suicide-related material (which may include voluntary assisted dying).

Our contention is that VAD is not suicide. We note some common characteristics of suicide:

- Mental illness
- The person is usually physically well (but not always)
- Professional help may not be sought, may be difficult to access, or maybe ineffective
- The person chooses between life and death
- Suicide planning and action are done in secret
- Suicide is a violent act, carried out alone
- Government information about suicide is about prevention, NOT how to do it

This contrasts with VAD as follows:

- A person is not eligible for access to voluntary assisted dying only because the person is diagnosed with a mental illness,
- The person is dying from a physical ailment, otherwise would not qualify for VAD
- Professional consultation is a key part of the VAD assessment process
- The person is close to dying (otherwise the person doesn't qualify for VAD) and chooses only time, place and circumstances of death
- The VAD process requires careful and deliberate assessment and planning with two medical practitioners involved
- VAD is not a violent act
- VAD is actioned in calmness, often in the presence of a medical practitioner and family and friends, not alone and in secret
- There is extensive government information about how to access VAD

We consider the whole matter is open to challenge, and are considering ways in which this might be done.



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ON BEING A WITNESS

BY JANE MORRIS (DWDV BOARD MEMBER)



Not everyone is aware that navigating the Voluntary Assisted Dying process can be complex and basically a hard slog for many patients and medical practitioners alike.

In addition to the mandatory consultations patients have with their medical practitioners, there is also the need for witnesses to be present when the necessary documentation for a final VAD request is completed. There are formal requirements in place as to who can qualify to act as a witness.

This can prove to be very onerous for some, if they find the range of people they may ask to act as a witness severely limited or in some cases non-existent. This could be the case especially if they are reluctant to ask

family members or close friends to become involved.

DWDV became aware of this difficulty and set up a list of volunteers willing to act as witnesses for these often-desperate patients.

I attended my first “witnessing” and found the brief process extremely powerful and one I have since constantly reflected upon.

The environment I found myself in, on that occasion, was positively uplifting and reaffirmed to me that the process of VAD is indeed humane, dignified and absolutely necessary.

The profound relief, that the final paperwork was being completed and the end of her suffering was close, was evident on the face of ‘Lady D’, and she constantly expressed her gratitude for our help.

‘Lady D’ had planned for her death with almost military precision, selecting a date which would cause the least amount of inconvenience for her family, friends and all those who would inevitably become involved in the associated proceedings in the aftermath of her death.

The brief discussion that ensued was uninhibited, frank and so very comfortable. She was entirely competent and aware of the consequence of the voluntary action she intended to take. ‘Lady D’ was going to embrace her death.

For the terminally ill who are suffering and solaced by the fact that VAD is now a legal option in Victoria, I cannot bear to think of a scenario in which they would be denied the opportunity to die a dignified death simply because of an obstacle that we can ensure is easily traversed.

For those of us that so strongly advocated the implementation of VAD in Victoria, we must now strive to make the process as straightforward and undemanding as possible for all concerned.

I felt so privileged to be able to help one individual in this small way.



VOLUNTARY REFUSAL OF FOOD AND FLUID: A CASE STUDY

Recently Dr Rodney Syme (retd.) was contacted by the husband of a woman who could not qualify for VAD, but whose life was a misery. The woman had had a stroke in 2017 and became bedridden. She also suffered dysphagia and was PEG-fed⁽¹⁾, so was unable to take any nourishment or hydration in oral form. She had suffered numerous episodes of aspiration of food into her airways.



After three years of distress, the woman decided to seek other information. On her behalf her husband contacted DWDV, who offered the facility to talk with doctors who could assist in considering options for treatment. She became aware she had the right to cease her medication at any time of her choice.

The major medication for her survival came from the PEG feed, on which she was totally dependent for hydration and nourishment. She decided to cease her dependence on the PEG feed on 2 February 2020, a consequence of which would be that she would die of dehydration in a few days.

This action is not considered to be suicide. The doctors promised they would respect her wishes and would do all they could to see she did not suffer.

Her husband reported: *"Our doctors were as good as their word and she didn't suffer apart from dryness of her mouth, eased by me and the nurses giving her ice at times. My precious wife died at 10.35pm on 10 February 2020, quietly and without any obvious distress."*

The point is that, with suitable assistance, you can achieve a good death even if you do not qualify for VAD.

(1) Percutaneous endoscopic gastrostomy

Full story: <https://www.dwdv.org.au/news/voluntary-refusal-of-food-and-fluid-a-case-study>

COVID-19

Our worlds have all been markedly changed by the impact of COVID19. Some of us find ourselves with extra time now in which we can reflect upon our lives and the lives of others.

Many of us are consumed by the constant barrage of viral related media releases and it can become easy to forget about others such as the terminally ill. Their suffering existed before the outbreak of the pandemic and will continue throughout and long after the pandemic has run its course. The torturous suffering of the terminally ill has been further compounded by the current environment of fear and panic that is overwhelming society.

DWDV would like to assure all those individuals that you have not been forgotten and that we will continue to do everything we possibly can to help you. The DWDV Office is still functioning as normal. To all our members, friends and families, we are thinking of you. Please take care.

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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.