Newsletter #188, Jun 2020

Dying With Dignity Victoria

Respect the right to choose est. 1974

DWD GROUPS CONTINUE COLLABORATING

Following the very successful conference of DWD groups from around Australia in March (just before the pandemic hit!), the first of what will be a regular series of follow-up Zoom meetings was held on 2 June.

Present on the call were Jos Hall (Qld), Penny Hackett and Shayne Higson (NSW), Hugh Sarjeant and Meredith Doig (Vic), Frances Coombe (SA), Judy Dent (NT), Steve Walker (WA) and Kiki Paul (GGA). Margaret Sing (Tas) was unable to join due to urgent family commitments.

Everyone was disappointed about the situation in Qld, where the premier has ruled out bringing a VAD bill before the parliament prior to the state election in October. The outcome of the election will be crucial to any hopes of a bill in the foreseeable future. Former National MP Jan Stuckey is on the record as saying that no Liberal-National would dare cross the floor on the issue, even if there is a free vote.

In Tasmania, Kiki reported that two sisters, Jac and Nat, are mounting a great campaign in memory of their mother, who died from gastric cancer in September 2019 (check it out at www.doingitfordisey.com.au).

In SA, Frances reported that a draft VAD bill is due by September. However, this is likely to be a private member's bill and traditionally private members' bills lack the resources and broad support to get up.

Meanwhile WA is working on getting their newly-minted legislation ready for operational implementation, due mid 2021; and in NZ, there will be a referendum on VAD on 19 September.

The group talked about how build a broad coalition of supportive allies and, at the same time, counter the widespread view that medicos are opposed to VAD; and generally how to share the knowledge, skills and resources resident across all these amazing volunteers as efficiently as possible.

We are investigating what would be the most suitable platform that would act as a repository for documents of general or long-term interest. Some articles from Rodney Syme are an example, and will be uploaded when the choice is made.

We are also seeking to build a list of doctors who are ‘in support’, in conjunction with DWDNSW.

We move forward and will not retreat!

VAD – ONE YEAR ON

BY JANE MORRIS

“It was a beautiful, positive experience,” said the two daughters of the first Victorian to utilize the Voluntary Assisted Dying Legislation.

For all those that had fought so hard and had invested so much raw emotion, time and energy into ensuring that VAD became legislated for in Victoria, these words were reassuring and validating.

June 19, 2020 will mark the anniversary of the implementation of VAD Legislation in Victoria.

In addition to the relief the legislation has provided to those suffering in the end stages of a terminal disease, we must also acknowledge the wide-ranging effect this legislation has had on the extended Victorian community.

The families and friends of those who have been afforded the ability to die in a manner and in a time of their own choosing have not had to stand by watching a loved one suffer inhumanely. They will not be haunted by the horrific images of a loved one dying torturously, nor will they be plagued by a lifetime of guilt because they failed to accede to the requests of dying ones to end their lives.

During this past year, we have come to acknowledge the number of individuals involved in ensuring the efficacy of the VAD practice. Most notable are the amazing VAD Care Navigators whose vast and demanding job description defies comprehension, and the doctors who have tirelessly and selflessly devoted their time and emotion into helping those in need.

It is vital that the incredible courage and commitment displayed by these few VAD practising doctors, especially during the COVID19 pandemic, is acknowledged and commended.

In addition, DWDV is extremely grateful that a number of its members agreed to take part in its voluntary witness and contact person program. This is such an integral and valuable role to play and has been greatly appreciated by patients, their families and medical professionals.

Finally, we must never ever forget the brave and selfless individuals who spent their final precious days sharing the most personal and distressing details of their end of life journeys. They valiantly fought to raise awareness of the critical need for VAD legislation to ensure that in the future others would not also die accompanied by great suffering.

Fortunately, their fight was not in vain.

dying with dignity victoria

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WEBINAR FOR DOCTORS, MAY 2020

BY DR NICK CARR

On May 28 I took part in a Webinar about Voluntary Assisted Dying (VAD) aimed at GPs. It was organised by Sue and Mel, the Navigators from Peter McCallum, and included myself and Greg Mewett, a Palliative Care specialist and VAD provider from Ballarat. It featured a brief outline of the VAD process from Mel, followed by Greg and myself responding to questions from the audience.

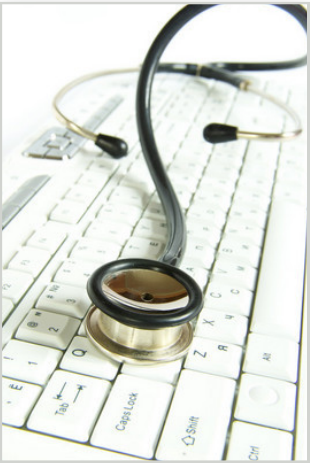
The webinar was fully subscribed, with 100 registrants from around the state eager for information. They were asked at registration about their views on VAD. There was a fairly even spread of GPs, from the curious-but-uncertain through to those planning to do the training, as well as 5 already trained.

There was also a smattering from research, DHHS, counselling and others. Pleasingly the whole state was represented, with plenty of interest from non-urban areas.

Registrants were also asked what content they were interested in hearing covered. Again, answers covered the whole spectrum; the nuts and bolts of the legislation and training, legal aspects, how to help patients, questions about access and the role of the Navigators. Practitioner administration (where the patient is unable to swallow, and the medication is given by the doctor) was a particular area of concern for some.

Mel did a great job of running through the VAD process, timelines and legislation, and then she and Susan moderated the Q and A session. All of the above questions were addressed and, as is the nature of these things, the hour seemed to gallop by, leaving plenty left for another session.

Registrants were sent a follow-up document with written responses to the questions that did not get addressed.



The ubiquitous feedback form was actually completed by the majority of the audience. Responses were uniformly positive, leading me to suspect that Mel tactfully disregarded anything from the disgruntled and dissatisfied.

Most pleasingly, of the 25 who said in the pre-webinar questionnaire that they were not planning to do the training, 6 said they had changed their minds and were now planning to do the training.

Huge thanks to the ever-amazing Navigators for organising everything. A reminder that they are there to help if anyone, health care worker or patient, has a query about VAD - vadcarenavigator@petermac.org.

The webinar was also a reminder that we still don’t have enough doctors trained in VAD care, so if you haven’t already done so, give your doctor a gentle nudge.

VOLUNTARY ASSISTED DYING: HOW IT CAN IMPACT JPS

Feature article from Custodes, the newsletter of the Royal Victorian Association of Honorary Justices (issue 3, 3 Nov 2019).

This is a true story. The names and locations have not been included in order to respect the privacy of all those involved.

A member JP recently witnessed the signing of a declaration by a very ill person formalizing the decision to request access to Voluntary Assisted Dying [VAD].

For some, this issue raises questions of morality, of religion and of personal rights. It can be confronting, challenging, emotional and at the same time incredibly rewarding, to play a tiny part in the much bigger picture that is VAD.

Victoria became the first Australian state to pass legislation allowing Voluntary Assisted Dying on 29 November 2017. The law gives anyone suffering a terminal illness with less than six months to live the right to end their life. The law had an 18 month implementation period and came into effect on 19 June 2019.

As the leading independent witnesses in the state, JPs may from time to time be requested to witness the execution of the forms required by the legislation. The process does not mandate that the witness be a JP, but as you know, the public often rely on us for these sorts of things.

The very thought of Voluntary Assisted Dying can be an anathema to some people in the community, including JPs. If you are not comfortable with being involved, feel free to say so and graciously request that an alternative witness be found. This same opportunity is afforded all healthcare workers involved in the new process as well.

If you do choose to be a witness, then the role is fairly simple. In practical terms, there are three stages involved before the completion of the entire procedure. Being a witness to the written declaration is step 2 of the process and is where a JP may come in.

It can be daunting when you read the information for witnesses to the written declaration produced by the Health and Human Services Department [Form 3], where the instruction is for the witness to:

“Ask the person how they reached their decision to request access to Voluntary Assisted Dying. You do not need to agree with their reasons or think that their decision is wise. You must also be satisfied that they are not being pressured by someone else to request access to Voluntary Assisted Dying.”

This gave our JP pause for thought as she felt it very intrusive to be asking such questions in what is, at best, a delicate situation. Sure, she needed to know that they have the capacity to make the decision, that they haven't been coerced and are taking the action voluntarily, but once they had read the written declaration aloud, there was no doubt. Mind you, a different source [Guidance for Health Practitioners at p52], stipulates that “In the presence of the witnesses, the coordinating medical practitioner should take the patient through a conversation about their decision, their understanding of the implications of their request to access Voluntary Assisted Dying, and the potential risks and likely outcome of taking the Voluntary Assisted Dying medication - noting that it will lead to the death.” That second scenario looks to be a more realistic approach.

"For the person wanting to make the declaration, the lead up to this moment had been very comprehensive. The person's coordinating medical practitioner and consulting medical practitioner had already assessed the person as eligible for Voluntary Assisted Dying. You will all no doubt know that person who makes this application must be over 18, a resident of Victoria for 12 months and the prognosis must be that the illness will be terminal within weeks or months, not exceeding six months, and is causing suffering to the person that cannot be relieved in a manner that the person considers tolerable. In the case of the neurodegenerative disease, life expectancy should not exceed 12 months.

This is how it happened in the situation I attended: The parties gathered in room - the doctor, the patient, a member of the patient's family, another health worker and the witnesses. They were all introduced to each other and if the patient thanked them once for agreeing to help her, they were thanked 15 times. The doctor then led the patient through the questions about how the decision was reached, whether or not the consequences of it had been considered and if the process was being undertaken of her own free will.

It was blatantly obvious the patient welcomed the opportunity participate in the VAD process. The Act specifies the wording of the written declaration she signed [s. 34 Form 3] and left no doubt as to her wishes.

No interpreter was required [there is provision for one] and the patient was able to express herself adequately without the need for intervention by someone else, although there is provision for someone to sign on their behalf, in which case the patient must show their agreement by a gesture.

For me, it was not the confronting or traumatic situation I had feared it could have been. As a JP, the role is, in its simplest interpretation, merely witnessing a signature. The relief expressed by the patient for my willingness to assist completing that stage of the process was touching."

There is no doubt our JP will assist again if asked.

A special Thank You to the JP Member who shared this true story in order to help us all be aware and prepared for the possible challenges which we may be asked to face under this new legislation.

AN UPDATE ON VAD: (ALMOST) A YEAR IN REVIEW

BY DR CAMERON MCLAREN

This comprehensive article by Dr Cameron McLaren reviews the experience of Voluntary Assisted Dying in Victoria since it became legalised almost a year ago.

He includes a reflection on his own experience - the impact on himself as well as his family - and examines what has been working and what needs to be improved in the way in which the VAD legislation has been implemented in Victoria. As he says: " *...providing VAD assessments has been a truly rewarding experience, peppered with bureaucratic frustrations and the occasional difference of opinion. There are aspects that are working, aspects to improve, and aspects for other states to learn from. But learning relies on the interpretation of data. The scientific method requires us to measure our outcomes and modify our approach to problems to improve systems. We need to collect data, the VAD Review Board needs to release their data, and we need to analyse all data with transparency*."

Read the full article here: https://www.dwdv.org.au/news/an-update-on-vad-almost-a-year-in-review

DOES THE VIC VAD ACT FULFIL ITS STATED POLICY GOALS?

An academic paper by Ben White et al says no.

The paper lists six policy goals:

- respect all human life
- respect personal autonomy
- safeguard the vulnerable and the community
- provide high-quality care
- respect individual conscience
- alleviate human suffering (compassion)

Two of these were particularly dominant in framing the VAD Act: respecting autonomy and safeguarding the vulnerable and the community.

The paper concludes that "**Limiting practitioner administration** of VAD to those who are physically unable to administer or ingest the medication themselves is **not consistent with the policy goals** of the VAD Act. In particular, **respecting autonomy** and providing high-quality care **would favour allowing eligible persons to choose whether to receive VAD by self-administration or from their medical practitioner**. This allows a person both greater choice as to the manner of their death and access to the safer of the two options. **Arguments about safeguarding the vulnerable lack traction** in this setting, given that practitioner administration is permitted by the VAD Act with appropriate safeguards, therefore recognising practitioner administration as a safe VAD option."

Download the full paper here:
https://www.dwdv.org.au/news/does-the-vic-vad-act-fulfil-its-stated-policy-goals

(*Our thanks to Ben White and the UNSW Law Journal for permission to share this paper.*)

ONLINE PRESENTATIONS

DWDV has been providing presentations to live audiences about Advance Care Planning (ACP) and Voluntary Assisted Dying (VAD) for close to 20 years. We are now investigating having online presentations that will support folk who are unlikely to come to any future face-to-face events.

These will be short and focused explanations about ACP and VAD. Our potential audience is, of course, our members but also members of the public, especially in regional Victoria, for whom we would like to provide better service.

Our first cab off the rank will be a conversation about VAD between two doctors – Nick and Cam – who are both members of the DWDV Board, very active in VAD support and excellent speakers. Watch out for the announcement of this launch!

Please think about how you access online information and send your requests for online presentations to the DWDV Office. We are really keen to learn about what topics people would watch and listen to, as we want to meet needs in the best way that we can.

WITNESSING IN THE TIME OF COVID-19

BY CARMEL MCNAUGHT

Having Voluntary Assisted Dying (VAD) legislation in place has been a magnificent achievement for many tireless lobbyists in the Victorian community, including many DWDV members.

DWDV enthusiastically launched into supporting the enactment of the legislation, including setting up a register of volunteers who would act as witnesses for folk making a VAD application. Then the disaster of the Covid-19 pandemic struck. Many of our volunteers were in the Covid-19 at-risk group because of age and health issues.

I am technically in this group (>70) and I had to make a decision about my own preparedness to be a volunteer. However, I am healthy and the need to support folk in the community to have a good end of life is important to me. So my husband, David, and I decided that we would welcome the opportunity to act as witnesses and have witnessed on two occasions. I will be honest: we have been living in isolation and entering a hospital required us both to take a deep and calming breath – and yet another dose of hand sanitiser!

However, we are both so pleased that we provided this service. On both occasions, the patient and his wife (who would act as the contact person for the medication) were calm and relaxed. The angst of the VAD decision was long gone; they were just grateful to have support for their decision and glad that they had a dignified option for the death that was coming soon.

We felt privileged to be able to offer our support. We chatted together for several minutes about the weather and family, as if we were meeting socially. Once we got to the business part of the meeting, it was clear they were well-informed about their decision, especially the aspect that receiving the medication does not mean that it has to be used. As witnesses, David and I had to feel confident that both the applicant and the contact person did understand the VAD process. Both doctors were superb – very clear about the protocol but friendly and caring.

The meeting does not take long and, on both occasions, David and I came home having had a powerful affirmation of how humane and just VAD legislation is.

DWDV VOLUNTEER WITNESSES

We are very pleased to have 136 people, so far, who have volunteered to act as Witnesses or Contact Persons in the VAD process. The Witnesses are required to certify that the person seeking the VAD service still has decision-making capacity; Contact Persons would be required to deal with any unused medication.

Since the lockdown and to minimise the risk to all involved, we have limited the call for volunteers to those people we are in contact with who are known to have no health issues. We have been able to meet the demand, but the frequency of requests has been higher than expected, and often at short notice. As the possibility of a threat from the virus reduces, we will seek to make use of more of those who have volunteered. To date, we have made 39 witness statements for 24 people wishing to access VAD.

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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.