

Dying With Dignity Victoria

Respect the right to choose est. 1974

PRESIDENT'S UPDATE

HUGH SARJEANT

Congratulations, Tasmania! On 23rd March legislation passed in the Legislative Council, making Tasmania the third Australian state to legalise Voluntary Assisted Dying. An amazing result – a private member's bill with a Liberal government. Special praise should be given to independent MLC Mike Gaffney, and sisters Jacqui and Nat Gray, who worked tirelessly in recent years to make this possible.

This will provide for around 39% of Australians or 59% if, as expected, Queensland follows. It is interesting to see what the arguments are for each State having different legislation. For South Australia, debate on the VAD Bill 2020 commenced in the Legislative Council on 17th of March.

The Tasmanian Bill is interesting in that it permits audio-visual provision of information after the first consultation – an example of telehealth. The Victorian Department of Health and Human Services (DHHS) is either unwilling or unable to address a serious impediment to the provision of the VAD service by prohibiting such a method. We are very grateful to Stuart Grimley MLC for raising this issue in parliament, asking a question of the Health Minister. He, and we, are patiently waiting for an answer. We also have an important ally in the Royal Australian College of General Practitioners (RACGP), whose Chair has written to the Victorian Attorney-General seeking a discussion in relation to the DHHS's instruction that there be no provision of VAD services via telehealth.

In Victoria, progress has been steady and well done. The three doctors on our Board - Nick Carr, Cam McLaren, and Rodney Syme - continue their good work in VAD provision, advocacy, and counselling. DWDV has been assisting with the implementation of

our VAD Act, including providing Witnesses when required.

The 4th report of the Voluntary Assisted Dying Board (VADRB) provided a very positive progress report. The report included quite comprehensive statistics. One of these referred to 6 cases of non-compliance of which two were by members of the public not returning unused chemical, within the legislated timeframe and four by a doctor who fell foul of confusing paperwork. All eligibility requirements were still met in these cases.

It is of concern, however, that about one third of those deemed eligible did not receive treatment. It would seem that the public is unaware of the delays that occur after first seeking VAD.

A copy of the report can be obtained from the Safer Care Victoria website at:
<https://tinyurl.com/ydkbaw7n>

For all VAD applications where a final request was made, 25 per cent were progressed between the first and final request within 11 days, and 50 per cent within 17 days.

The Territories languish in their Kevin Andrews-induced state of 'no option for VAD', but we have had Tara Cheyne (ACT) and NT Attorney-General Selena Uiibo write to the federal Attorney-General seeking restoration of the territories' ability to make their own decisions on such issues. Additionally, Andrew Leigh (ACT) and Warren Snowden (NT) have put forward a notice of motion, in the House of Representatives, to restore Territorian rights.



TELEHEALTH AND VAD

DR NICK CARR

In the second half of year 1 BCE*, i.e. 2019, the first doctors who had trained to provide VAD care were contacted and reminded that all VAD assessments and consultations MUST be carried out face to face. As access to VAD had only just begun, and none of us had any experience in doing the work, this didn't seem too big a deal.

That naïve assumption was challenged for me just the next week, when I was contacted by a man in Echuca. With a degenerative neurological disease, there was no one local who was trained in VAD care and could help him. He was in a wheelchair and needed a full-time carer.

When I told him he would have to come to Melbourne for each assessment, he responded with some choice Aussie vernacular.

I learned a few new words that day.

It rapidly became apparent that - surprise, surprise - the people who most needed VAD care were often sick and struggled to travel. The requirement that all assessments be done face to face was already placing an unreasonable burden on both patients and doctors.

And then Covid hit.

Amongst all the pandemic pivoting that went on was the rapid adoption of telehealth. A timely, modern and safe solution that has proven to be more effective than anyone imagined - but an option still denied for VAD care.

So why is this?

It comes back to the Commonwealth Criminal Code Act 1995, which restricts the use of carriage services for purposes broadly relating to suicide. The law was designed mainly to stop kids bullying and telling others to kill themselves. It was never intended to apply to VAD (which was not legal anywhere in Australia when the law was framed). However someone, somewhere deep in DHHS Victoria decided that the Code applied to VAD care; hence the instruction given to us in 1 BCE.

We at DWDV have always contended that the Commonwealth Carriage Service law does not and should not apply to VAD. As discussed in this Newsletter last year (#187, April 2020), VAD is not

suicide. It is a legally valid medical option. As we said then, "We consider the whole matter is open to challenge, and are considering ways in which this might be done."

Since then, we have obtained an independent legal opinion, which states there is no clash between the Commonwealth law and the provision of VAD care. The WA Attorney-General has written advising that he reached the same conclusion for the provision of VAD care in WA. Further support for this view comes from a scholarly article written by experts in medical ethics and the law**.

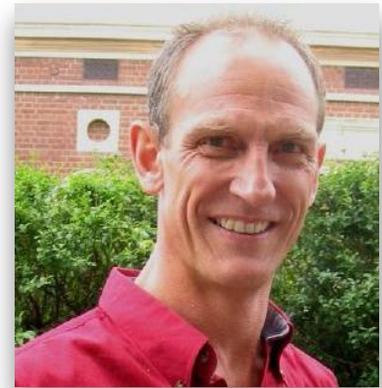
Armed with this support, DWDV has approached health ministers and AGs, both State and Federal. The outcome has been expressions of concern, circular buck-passing and a reluctance by anyone to actually change anything. As a result, we have looked for support elsewhere. Currently various other avenues are being explored:

- RACGP Victoria have written to Jaclyn Symes, MLC, Victorian Attorney-General, seeking her review of the interpretation.
- The Law Institute of Victoria have written to Ms. Elizabeth Curtis, Commonwealth Director of Public Prosecutions, seeking her views.
- Stuart Grimley, MLC, asked a question in the Victorian Parliament of the Health Minister, Hon Martin Foley, seeking further information, and a reassurance that doctors could not be prosecuted for using telehealth.
- The Australian Magazine is shortly to publish a long-form article on VAD, which we hope will touch on the telehealth issue.

We'll let you know if and when any of these bear fruit.

* *Before Covid Era*

** *Journal of Law and Medicine, (2020) 27 JLM 839, "Suicide-related Materials and Voluntary Assisted Dying" pp 839-845, published 17 August 2020.*



REACHING OUT TO ALL LANGUAGE GROUPS FOR ADVANCE CARE

PROF CARMEL MCNAUGHT



DWDV is very conscious that Victoria is a diverse community. This diversity adds significantly to the cultural and economic wealth of Victoria, but presents challenges in terms of supporting

meaningful discussions about the myriad of issues surrounding planning for the end of life. Supporting Advance Care Planning (ACP) is not just a question of providing information. The process requires lots of personal soul-searching about one's own values about life and one's own wishes for the last phase of life. In-depth discussions with family and friends are also essential to the process. This type of intimate, personal decision-making can only be done usefully in the language in which one thinks and feels. For many community groups in Victoria, this is not English.

During the past few years, DWDV has provided some sessions about ACP in Chinese that have been translated bit by bit during the session. This dual-language approach has led to some excellent discussions, but it is a tad fragmented.

So, I am delighted to report that DWDV has had our first Chinese-language (Cantonese) ACP session (via Zoom).

Yen Kim (Active Connection Worker/ Chinese Access and Support Worker for cohealth; <https://www.cohealth.org.au/>) led the session which flowed beautifully and led to searching questions from participants. We hope to be running more sessions in Chinese later this year.

DWDV is very keen to develop this model of partnering to reach communities where communication is often best in a language other than English. We are all hopeful that we can return to face-to-face presentations and discussions at some time in 2021. With both online and face-to-face interactions possible, DWDV is hopeful that we can provide a truly meaningful ACP service for a greater number of Victorians. To that end, any community group that wishes to explore this partnering model is warmly encouraged to contact the DWDV Office.



Is your paperwork up to date?

An Advance Care Directive (ACD) conveys your medical treatment wishes if you are not in a position to do so yourself. ACDs signed and correctly witnessed on or after 12 March 2018 are legal documents, those signed before this date will be taken into consideration by doctors but are not legally binding.

If you require a new ACD, or need to appoint a Medical Treatment Decision Maker, the forms and instructions can be downloaded from our website: <https://bit.ly/2KdXKP4> To request that forms be posted to you, please contact the office at office@dwdv.org.au or by phoning 0491 618 732.



Email: dwdv@dwdv.org.au

Phone: 0491 718 632

Address: PO Box 743, Kew, VIC, 3101, Australia

AGED CARE FACILITIES AND VAD

SUE CUMMINGS

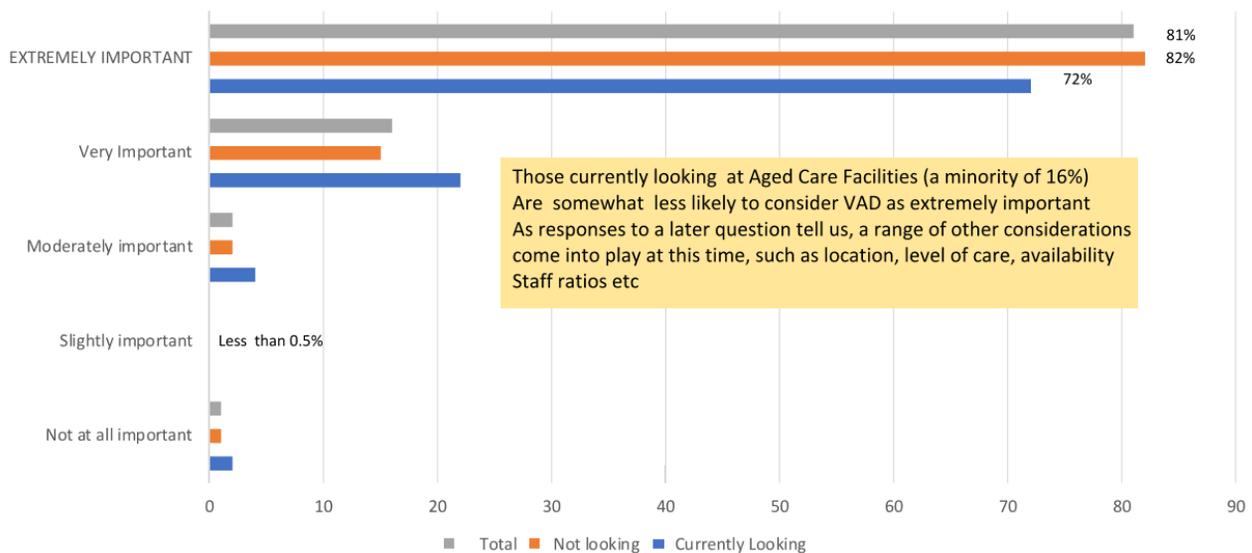


We recently ran a short survey among a random sample of our members on the subject of Aged Care Facilities and Voluntary Assisted Dying (VAD).

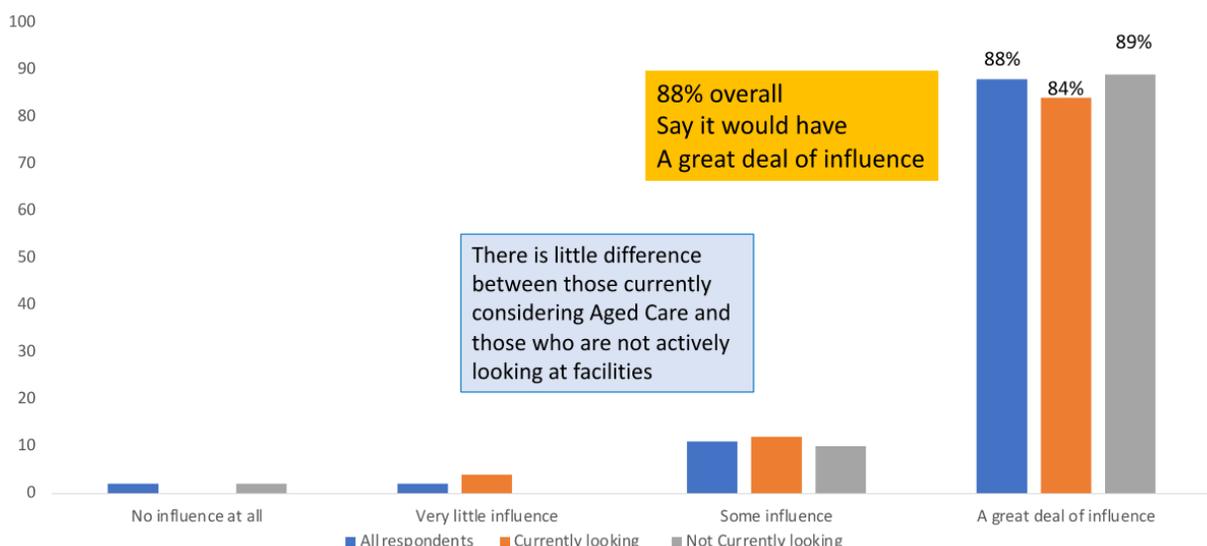
As you probably know, not all aged care facilities in Victoria support and facilitate VAD, and we thought it might be good to know which ones do (and which do not).

And it is clear our Members agree that a list of Aged Care Facilities which support VAD will be of value.

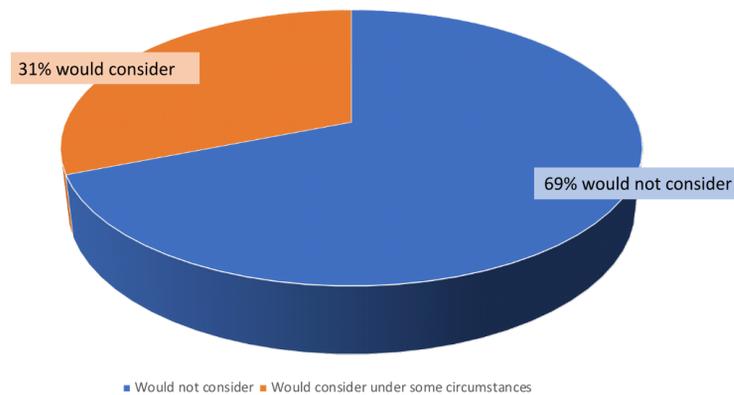
Whether or not you are currently thinking about Aged Care for yourself or someone else, how important would it be to you that the Facility you are considering supports VAD?



How much influence on your decision, now or perhaps in the future, would access to VAD have on your choice of an Aged Care Facility?



Would you ever consider an Aged Care Facility for yourself or someone else which does not allow VAD?



Can you please describe the circumstances under which you would consider an Aged Care Facility which does not support VAD?

Reasons for considering facility not supporting VAD	All who would consider a facility which does not support VAD	Currently looking	Not looking
More convenient location	52	(65)	49
Better facilities	57	(61)	51
Costs	25	(23)	26
Don't know	6	(4)	7
Something else	37	(38)	35
No other facility available (particularly regional areas); emergency short term respite care; access to GOOD palliative care; Dementia, Alzheimer's; have a GP who would administer it at a relative's home			

DWDV Board Members are now busy working on preparing the listing, so that your choice of which aged care facilities to consider will be better-informed, should residential care for yourself or another become necessary.

A big thank you to all of you who completed the survey if it was sent to you.

Here are a few of the comments made at the end of the formal questions:

"A wonderful idea. I would be greatly relieved to have such a list as herein proposed."

"Having had a mother and husband spend their last years in a care home, the most important criteria for my choice would be as perfect facilities as possible, good staff/resident ratio ... Agreement for dying with dignity would be the cream on the cake!"

"This is a very important question for many of us, so I hope you are able to compile a comprehensive list."

"Why should VAD be limited to only some aged care facilities? No matter where the patient is living, whether at home, in palliative care or in a nursing home, it is everybody's right to apply for it."

PALLIATIVE CARE AND VAD

DR RODNEY SYME

Palliative care is one of the most important developments in modern medicine in the last 60 years. Developed in the United Kingdom in the 1960s by Dame Cicely Saunders, it aims to provide compassionate and holistic care to the terminally ill. It is now an established medical speciality with specially trained nurses and doctors, and its own care institutions. It also aims to cope with social, psychological and spiritual needs. It is undoubtedly the most effective agency for dealing with cancer pain. It provides enormous benefits for most people at the end of life.

However, meeting all the needs of dying people is a formidable task. In 2009 I formulated 6 medical givens, or self-evident truths regarding the end of life. They are that:

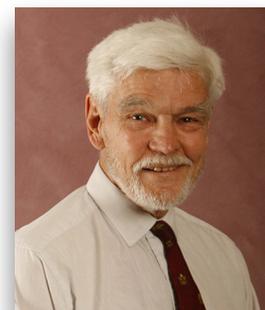
1. dying may be associated with intolerable suffering, and there may be a crescendo of suffering as death approaches
2. Palliative Care cannot relieve all the pain and suffering of dying patients
3. some suffering will only be relieved by death;
4. some people rationally and persistently request assistance to die
5. it is a doctor's duty to relieve suffering
6. it is a doctor's duty to respect patient autonomy

These principles are generally accepted by the medical profession, except by some in palliative care, especially the sixth given.

Palliative care was founded by a deeply religious woman and it embraces strong moral principles, one of which is that it does not hasten death, which brings it into conflict with the six givens.

If you are in palliative care, suffering intolerably, and both rationally and persistently requesting a hastened death, you will very likely be denied. This is because most palliative care is provided by Catholic institutions or other religious groups. This dominates practice and influences the underlying accepted philosophy of palliative care, which is opposed to Voluntary Assisted Dying.

Palliative care's remit is to relieve suffering, but it cannot deal with suffering of which it is unaware. Most of the end-of-life symptoms cannot be measured by carers – they are what you say they are. So do not minimise your symptoms, communicate them forcefully and frequently – your carers are obliged to respond.



Nevertheless, palliative care acknowledges 'refractory symptoms' which cannot be relieved by standard care (this is equivalent to intolerable suffering) and this allows for terminal sedation for relief. Terminal sedation involves putting such a patient into a coma with continuous administration of sedatives and usually analgesics, and without fluids, until they die.

Such deep sedation is palliative care's answer to VAD. However, the decision to use this process and the rate of administration of medication are controlled by the specialist doctor, not the patient, and usually the drugs are titrated - that is gradually increased in response to unrelieved suffering, sometimes over days. This clearly can hasten death, although most in palliative care deny this, and there are some who refuse to use such a means of symptom relief. There are also a few who use such sedation in a more appropriate and effective manner. Such is the lottery of palliative care. Nevertheless, terminal sedation is a benefit to many, does minimise suffering and may hasten death; so accept it if it is offered, or ask for it if your suffering is being ignored.

The Victorian guidelines for terminal (palliative) sedation allow patients to request such sedation, but most do not know it is possible, are not advised of such, and therefore cannot ask. Most people who are dying in palliative care are in a weak position to have an influence on symptom relief, and the presence of an informed advocate to observe and argue for improved care is very valuable. Effective communication can make a big difference to outcomes, and a clear Advance Care Directive can be invaluable.



ADVICE ON ENGAGING WITH PALLIATIVE CARE

DR RODNEY SYME

1. Palliative care (P/C) can provide excellent relief of pain and skilled nursing support, but it is not perfect, so if it is not meeting your needs use it intelligently and seek sound alternative advice. You can withdraw from P/C for care at home.
2. If becoming involved with P/C, establish early their attitude to VAD.
3. P/C is excellent for assisting with home care management, though usually in an advisory role as it is often understaffed.
4. Do not minimize your suffering – P/C is obliged to relieve your suffering, and they cannot measure it. Be persistent in your requests – do not be patronised.
5. Ask questions on admission about their policy re relief of symptoms and use of palliative sedation. Be aware that you can ask for palliative sedation to be considered in the future or used imminently.
6. Make sure you take your **Advance Care Directive** to P/C, ensure it is registered and acknowledged, and refer to it to ensure it is not ignored.
7. If possible, have a relative or friend with you as much as possible for support to ensure that your requests or complaint of suffering are not ignored or minimized.
8. If you are destined to die in P/C, do not ask for hastening of death (euthanasia) but ask for more effective relief of suffering.
9. You can pursue VAD quietly outside of P/C as a parallel process, since it is unlikely to be agreed to in P/C (belt and braces – use P/C for its acknowledged benefits but have an alternative up your sleeve if you need it). Be aware that completing the VAD process takes time - anything from 10 days to a number of weeks. Do not delay until very close to the end.

OUR INTERNATIONAL CONNECTIONS AND SOCIAL MEDIA PRESENCE

JANE MORRIS



I have always been impressed by the amount of support VAD organizations similar to ours have in other countries, and the fact that this enormous groundswell of public support has not waned since the passage of their respective Assisted Dying Legislations.

Late last year we held a Zoom meeting with 3 members of DWD Canada. We were keen to learn more about the direction their organization had taken since the passage of Medical Assistance in Dying (MAID) Legislation in 2016. We were also interested to learn more about the role that social media plays and how it is managed. It was a most informative meeting, as well as extremely enjoyable, and we hope to continue relations with 'our new friends'.

We have also reached out to The Netherlands

organization, NVVE. Thank you so much to our DWDV member, Ellen Dutton, for her beautifully translated copy of my email into Dutch! NVVE responded with some valuable and informative material relating to their organization's work.

It appears that social media plays a large and important role in the dissemination of news from the many Assisted Dying organizations around the world. DWDV would like to increase its presence in this field and endeavour to attract a larger audience with specific focus on a younger demographic. It is apparent that personal stories draw a lot of interest. In Victoria we are in the enviable position of being able to provide 'good news' stories that have eventuated as a result of our VAD Legislation.

We have a Twitter stream, that we recently recommenced, with a following of 116, and a Facebook page that, when active, has a following of 6,000. If you have access to these sites, please forward any suggestions to us regarding issues that you would like to see covered.

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