

Dying With Dignity Victoria

Respect the right to choose est. 1974

FROM THE PRESIDENT

HUGH SARJEANT

In terms of increasing the chances of getting VAD in other parts of Australia, it has been a very good year. At the time of writing we have had a vote in favour in the Tasmanian upper house, a commitment from the Queensland government to introduce legislation, and a bill is expected to go before parliament in South Australia by early December. It is notable that the vote in Tasmania was unanimous – the first such case in the world. Also, the result in the New Zealand referendum, with a 65% level of support, bears out the many surveys done in Australia.

To get improvements to the system in Victoria remains a challenge. Many of the defects identified by practitioners cannot be remedied until the review of legislation, scheduled for 2024. However, we have had a very useful opinion from barristers Robert Richter QC and William Stark. The outcome may be to remove the unnecessary impediment to using telehealth as part of the process to get approval for VAD. Particularly during the lockdown, prevention of even use of the telephone has created additional problems for all those involved. There are also some other administrative matters we may be able to address.

Of serious concern is the lack of a sufficient number of doctors, particularly specialists, who have done the VAD training and are thus able to contribute in the provision of VAD. The burden of providing VAD to the public then falls on too few, with a risk that that load may become too heavy and result in severe stress on the system. We are investigating a number of ways that may address this issue.

On a happier note, we have been the beneficiaries of generous donations. We seek to run as lean as is possible, but in order to provide service to our members and the community we need a base level of income. We also need to pay for some services.

The continuing of such donations makes it much easier to keep the show running.



We have not been able to run our normal presentations during most of 2020 and have sought other ways to get information out to the community. In part the need has been met by additions to the website and Facebook as well as the possibility of virtual presentations, one of which was provided in Cantonese. Doctors Nick Carr and Cam McLaren have been active in many ways, including making a presentation to the Tasmanian upper house. Board members have also been active in supporting the Witness Service, which is required by law to confirm that the person seeking VAD has decision-making capacity.

Doctor Rodney Syme AM has re-joined the Board. This step only changes the appearance, rather than the reality, of his level of support and involvement. We lose Vice President John Hont, who takes a break after 12 years of active service, but are joined by Sue Cummings, who has marketing expertise. Following our successful conference in March, our relationship with the other DWDs of Australia remains active. We benefit from a sharing of information and ideas, and now hold regular meetings to stay in touch and offer support in various ways.

We look forward to 2021. With the expected easing of restrictions, many activities will become less challenging and our level of some services can increase. As in general things seem to be going our way, it is easy to remain positive.

FINANCIAL REPORT

MARK NEWSTEAD (TREASURER)



Our organisation has always relied on its members to activate widespread community support. Part of this is being financially solvent, with adequate income to pursue our objectives and fund our campaigns and services for members and Victorians who will wish to avail themselves of the VAD rights now legislated.

Members have access to the full set of accounts, which are formally audited, and can be accessed on our website:
<https://www.dwdv.org.au/documents/item/296>

When we planned for the financial year 2019-2020, we knew our income was very reliant on donations and was hard to forecast. In our long existence, donations and especially bequests had provided the wherewithal to maintain service and run campaigns. But our assets were always being nibbled down to keep operating. We became aware significant donations could be had, but it was important for donors to be able to claim these as tax deductions.

To address this, we applied for Deductible Gift Status registration in 2018. It was a long and specialised process. Our past president, Lesley Vick, together with the much appreciated effort of Julian Ryan of FAL Lawyers (working for us pro bono), toiled assiduously to achieve DGR Status with the Australian Charities and Not-for-profits Commission (ACNC). Charitable foundations and monetary gifts or bequests to DWDV are now tax-deductible.

So what happened? It worked! In the financial year (2018-19) prior to DGR Status, the donations component of income was \$53,000. In the audited financial year to June 30 2020, donations more than doubled to a total of \$136,000 (all figures rounded to nearest thousands). That's like getting a 'pay rise' of more than double - from \$1k per week to \$2.6k per week. And the rate of donations for the first quarter of the current financial year (2020/2021) is also pleasing.

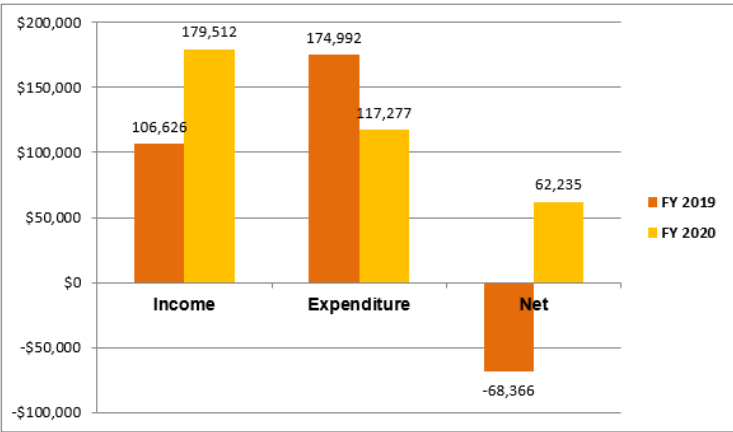
The full story also necessitated changes in the operational structure, reducing employment costs and the associated overheads of a rented office. We took advantage of a very Covid-19 shift to home office servicing.

This, together with Zoom meetings, has swiftly re-balanced the expenditure outlays and directed

a tripling in spending for member services including communication and outreach to public and member enquiries. For the current reporting period to 30th June 2020, DWDV closed with an operational surplus of \$62,235, compared with a loss of \$68,366 for the previous year, the loss being funded by asset reduction.

Although our efforts to bring legislation in Victoria have achieved the necessary milestone, we still have a way to go to advocate for refining and widening the Act's reach and accessibility. As the leader in achieving legislation, Victoria openly supports and encourages the efforts of other jurisdictions, including having made a campaign contribution to New Zealand's successful referendum endorsement of their VAD law - now being enacted.

Finally, with bank interest rates at record lows of less than one tenths of one percent, Term Deposit rates no longer represent a useful asset retention and building strategy. We have established a regular finance committee reviewing our investments. Commensurate with both ethically directed investments and our increase in donations, we are investing in Exchange Traded Funds to seek a better return on investment. This will be monitored closely but is still a long-term investment strategy, designed to underwrite the operational costs of DWDV's activity without having to draw down our asset base as we have done in the past.



A MESSAGE OF THANKS

DR PATRICK MCCARTHY



A few weeks ago, a close friend approached me for advice about her dying sister. The sister, Maree, had attended one of DWDV's community presentations. She, Maree, also thought that she had initiated the VAD process via the palliative care team which proved to be erroneous and Maree was anxious to follow this through.

I provided a broad overview but suggested she contact Natalie King, the Administration Manager at DWDV, who I said was very experienced in guiding people and opening the pathways of help. My friend, Joanne, took that advice and found Natalie terrific and most helpful.

Joanne subsequently had extensive contact with the Navigators that included at least 10 phone calls - many initiated by them with follow up information and enquiry regarding coordination of necessary appointments and provision of necessary information. Joanne expresses great admiration for the caring help the Navigators provided. She found their dedication and humanity to be outstanding.

Maree first met with her GP and subsequently Cam McLaren (Oncologist and DWDV Board Member) met with Maree for assessment and was happy to have Joanne present. Joanne described Cam's attention, compassion, sensitivity and competence as "wonderful". Joanne's sister Maree appreciated how Cam empowered her and how he provided her with the opportunity to tell her story in her own words rather than through the reports of others. He also gave the family and friends the opportunity for them to say goodbye via Zoom when he suggested the timing of the planned farewell be brought forward. Maree died before the original timing of the Zoom farewell.

Maree passed away on Wednesday September 30, 2020 before the VAD process could take effect.

Sincere thanks to Cam and Natalie and the three navigators for helping my friend Joanne and her dying sister Maree.

(Note: Names have been changed to protect privacy)

I remember speaking with Joanne, who is absolutely lovely, and she obviously provided fantastic support to Maree. I'm glad Maree got some comfort from the VAD process. I've seen Cam in action with a few different patients, when I have been a witness. He is absolutely amazing. The patients are so at ease with him and you can see how much he really cares about each individual and their circumstances.

Natalie King

Maree wasn't going to make it through the process from the outset, but I offered to see her to acknowledge and respect her wishes to pursue VAD nonetheless. It was an opportunity to reassure Maree and Joanne about palliative care and a great example of how access to VAD can improve the end of life experience, even if it is not able to be utilised. Joanne was a fantastic support for Maree. I'm so glad they rescheduled the farewell and they had that time together.

Dr Cam McLaren

What a sad but absolutely wonderful story that is so very heartening to hear. Within this newly implemented system it is so comforting to know that such personally directed care can be delivered on so many levels at the different stages of the VAD process. Victoria has achieved an extremely enviable practice of end of life care.

Jane Morris

Thanks Patrick for a clear, lucid story about your friend Joanne and her sister Maree. It encompasses the essence of what DWDV is able to do for anyone who seeks help, and it shows we act compassionately and sensitively.

Mark Newstead

CORPORATE GOVERNANCE AT DYING WITH DIGNITY VICTORIA

DR PATRICK MCCARTHY (VICE PRESIDENT)

The Organisation for Economic Co-operation and Development (OECD) in 1999 defined corporate governance as the system by which business corporations are directed and controlled.

DWDV Board of Directors

There are currently 10 directors at DWDV who undertake their duties according to established corporate practice, and in ways that are consistent with the organisation's Incorporated Rules which can be found on the DWDV website.

The board includes two medical practitioners - specialist oncologist Cam McLaren and GP Nick Carr. Also on the Board is Dr Rodney Syme, pioneering VAD practitioner in Australia. These doctors are intimately involved in the application of Victoria's VAD legislation.

The board also contains a former nurse, there are five people with professional business backgrounds and qualifications, two of whom have specialised in marketing and communications, and there is an internationally recognised educator.

Two board members have formal company director qualifications.

DWDV Board Activities

The board's medical expertise ensures that the Board's primary focus is always on today's medical VAD practice and issues.

The rest of us on the board use our skills to support the medicos, often through political interventions. Additionally, we communicate with the public and consciously seek to protect the reputation and assets of DWDV.

An independent audit of accounts occurs annually. The AGM is held in November each year and is open to members and others with an interest in VAD.

The board meets approximately every 6 weeks. There is much complementary/preparatory work undertaken between board meetings. Formal agendas for the board and subcommittees are prepared for all meetings; formal minutes are developed and approved for all meetings.

All documentation including policy development discussion is uploaded to a commercial electronic board management system known as "Boardable". This means that comprehensive historical records will be available to future board members.

DWDV Board Sub-Committees

Sub-Committee meetings take into account the timing of board meetings, as all important discussions and recommendations are brought to the full board for decision.

Strategy and **Finance** Sub-Committees have been established.

Planning is underway to establish a **Communications and Social Media** Sub-Committee. DWDV has recently re-engaged with Twitter and has had a long association with Facebook.

More traditionally, DWDV participates in a weekly review and distribution of media reports and has in pre-pandemic times held regular public information sessions.

The **Strategy** Sub-Committee meets at least quarterly but much more frequently when an issue is being addressed, such as political intervention seeking to overcome federal or state legislative conflicts associated with the use of telehealth by VAD medical practitioners undertaking patient assessment.

Another key issue is DWDV's challenge to an unfavourable interpretation of Section 10(3) of the VAD Act as it relates to "specialist" medical expertise in the assessment process. DWDV's view is that many GPs possess "relevant expertise and experience" in a dying person's complaint. This is important because it is not always possible to find an available specialist who has undertaken the required VAD training.



The **Finance** Sub-Committee meets every 3 months to review the profit and loss situation and the investment performance of DWDV. DWDV currently has 3 accounts. There is a small bank account to pay for routine expenditure as it falls due - such as office expenses and payments to our communication and social media consultants. The remainder of DWDV's money is invested conservatively, in equal amounts, in (a) a well-regarded Ethical Fund, and (b) a similarly well-regarded Diversified Fund.

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.

GOOD NEWS FROM TASMANIA

JANE MORRIS

There has been much excitement and extremely encouraging news from Tasmania in recent weeks for other Australian states and territories. Independent Mike Gaffney, MLC, introduced a private member's bill, the *End of Life Choices (Voluntary Assisted Dying) Bill 2020*, into the Tasmanian Parliament upper house. Despite not adopting the conventional approach of introducing a government sponsored bill into the lower house, the results so far have been nothing short of amazing.

In the upper house, after many hours of debate, suggested and approved amendments, the Bill was finally passed by a unanimous vote, 15:0. It is believed that this has never been achieved elsewhere in the VAD world. Indeed, an extremely positive sign of things to come.

The Bill was then referred to the lower house in early December. The resultant vote in favour of the Bill was a resounding 17:7 of MP's voting in favour. In fact, 18:7, if consideration were to be given to the vote of the LNP Speaker of the House, Sue Hickey.

This was the fourth attempt by the Tasmanian Parliament to pass similar legislation.

The speeches delivered by the majority of MPs were heartfelt and imbued with genuine compassion. It was heartening to see that so many MPs had engaged with their constituents, listened, taken into consideration their harrowing stories, and consequently voted accordingly.

Critically, several notable Liberal MPs, who had previously voted against VAD bills, voted for it this time around.

A final vote on the Bill is expected in March. In the interim, Tasmanian Premier Peter Gutwein has ordered that an inquiry be established by the University of Tasmania to report on the legislation. This report will be released prior to parliament resuming in the New Year.

Overall, 33 out of 40 Tasmanian MPs supported the Bill. This equates to 82.5% of MPs, which accurately reflects that of public opinion. (Thanks to Shayne Higson for this statistic!).



Such a result exemplifies that democracy is alive and well in Tasmania, and provides an incredible incentive for other states and territories to strive for.

Acknowledgment must be given to the indefatigable Mike Gaffney and his staff, the courageous efforts of Jacqui, Nat and Tilly Gray, in memory of their beloved mother Diane, and of course the solid, long term and unwavering commitment to the VAD cause by Dying With Dignity Tasmania.

We cannot, of course, fail to acknowledge the wise counsel provided to Tasmanian MPs by our Victorian heroes and board members, Dr Nick Carr and Dr Cam McLaren. We are so proud of you both!

Bravo Tassie, we await the New Year with a glass of champagne in hand.

MORE PROBLEMS WITH THE VIC VAD LEGISLATION

DR CAMERON MCLAREN



A woman had applied for VAD, been found eligible by two other doctors, been granted a permit, and received her oral medication. She then lost the ability to reliably self-administer the VAD medication and so needed Practitioner Administration (intravenous). The two doctors involved in her oral medication supply had not previously performed intravenous administration and were not comfortable with doing so.

This then introduced time-pressure to transfer the permit from Self-Administered to a Practitioner Administration, and dispensing of the intravenous medication.

If the patient has previously received a self-administration substance, the Act requires that this medication be returned even before a Practitioner Administration permit can be applied for. Fortunately, in this case the Voluntary Assisted Dying Statewide Pharmacy Service was able to respond immediately to retrieve the self-administration substance, but the pharmacy is often busy, and there is potential for several days' delay before the pharmacy may be able to retrieve and dispose of the self-administration substance.

The only person who is granted permission to administer a VAD substance to a patient is the Coordinating Medical Practitioner. The only ways to become a Coordinating Medical Practitioner are to:

- (a) accept a patient's First Request for VAD; or
- (b) be a Consulting Medical Practitioner who accepts a transfer of role from the Coordinating Medical Practitioner.

Definition (a) has more-recently been shown to be problematic – a patient may make a “first request” to any registered Medical Practitioner, but unless that Medical Practitioner is VAD-trained, it does not count as a “First Request” under legislation. This has now led to patients having to make multiple “first” requests.

The significance of this is the 9-day “cooling off period” required before a final request is made. I have not had any case change their mind within that 9 days.

The “cooling off period” is therefore superfluous, and creates legislative delays without contributing to

patient safety. Invariably, patients feel relief and a sense of reassurance after receiving their VAD medication, and this palliative “treatment” for their end of life anxiety should not be delayed by a legislative requirement that is not contributing to safety.

In this case, as neither the Coordinating Medical Practitioner nor the Consulting Medical Practitioner were prepared to provide Practitioner Administration, the case was at an impasse.

The eventual solution was to create a new case for this lady with the original Coordinating Medical Practitioner's assessment, to have me upload my assessment as Consulting Medical Practitioner, and then transfer the roles so that I could become the Coordinating Medical Practitioner and apply for a Practitioner Administration permit.

However, as my Consulting Assessment was now dated after the previously-completed Written Declaration, Final Request, and Contact Person Appointment, which then were rendered non-compliant. I had to re-attend this poor woman's house, complete another Written Declaration, receive her renewed Final Request, and re-appoint her Contact Person. The unintended legislative wording was now forcing this poor woman to continue to suffer much longer than should have been necessary.

I submitted the paperwork and implored the secretariat to expedite the processing of the application, and was at one point told that my “urgent” case was “sitting with the Secretary for review and permit outcome determination”, despite this woman previously being found eligible.

My feedback regarding this case has been that if a case is marked as urgent for clinical reasons it should not “sit” with anyone. Ultimately, the permit was

granted and staff at the Voluntary Assisted Dying Statewide Pharmacy Service stayed back to attend to the woman's house after hours. I administered the medication with no complications, drove the 1.5 hours back to my hospital, completed the ward round I should have been able to do hours before, got home after midnight, and went to my office the same day to submit her death certificate, Practitioner Administration Form, and notify the Coroner.

This process made me feel entirely alone, unsupported by both the legislation and the administrative processes involved, and exhausted.

VAD in Victoria is “working”, but it is not working as intended, and change is needed.

I am concerned that it will be difficult to make any changes to the VAD legislation at the first review after 5 years of implementation. These issues aren't going to be able to be presented and acted upon during the review; however, they need to be discussed and emphasised now so that change is expected when the review comes.

Regardless of the specifics of this case, it is clear people should start the VAD process early.

DWDV 2020 AGM SNAPSHOTS

This year, due to Covid-19 restrictions, we held our 47th AGM virtually via Zoom.

This was the first time our AGM has been held online. It was well attended and very successful.

The AGM also included a panel of four people involved in the roll out and operation of VAD in Victoria, who shared their experiences and expertise.



Hugh Sarjeant and **Dr Meredith Doig OAM**
DWDV President and DWDV Secretary



Panel Member
Dr Nick Carr
DWDV Board Member



Panel Member
Dr Cameron McLaren
DWDV Board Member



Panel Member
David Seymour
Lead Pharmacist
VAD Statewide Pharmacy Service



Panel Member
Dr Greg Mewett
Palliative Care Physician
Ballarat Health Services

THE RODNEY SYME MEDAL FOR 2020

DR PATRICK MCARTHY

The Rodney Syme Medal is awarded for distinguished and outstanding effort in pursuit of the Dying with Dignity cause.

Honorary Life Membership of DWDV accompanies the Award.

The Medal recognises Dr Rodney Syme, urologist and surgeon, who has been helping others to die with dignity since the mid 1970s when he helped a patient in extreme pain end his life. Since then Rodney has counselled and assisted more than 2000 people, as he agitated for law reform and has continued to advocate for improvements to the legislation, and to the associated system of medical practice.

Rodney Syme is a Member of the Order of Australia. The award was made "for significant service to social welfare initiatives, and to law reform". He has recently been nominated for the 2021 Senior Citizen of the Year Award.

The Rodney Syme Medal has been awarded every year, except one, since 2007.

In the early years the medal recognised people campaigning for social and Legislative change. The Medal was awarded to people like the dying chief executive of a large Australian company, Peter Short, media personality and Go Gentle founder and campaigner Andrew Denton, and Marshall Perron - a former Chief Minister of the Northern Territory. As many know, Andrew and Marshall remain very active and effective in campaigning for this cause.

Having laid the foundations for change, steering legislative change through the Victorian Parliament became the new primary task.

Politicians Gavin Jennings, who steered the Assisted Dying legislation through Victoria's upper house, and Fiona Patten, who was also central in steering the legislation through Parliament, were recognised for their substantial legislative contributions.

We are now in the third phase - the implementation of Voluntary Assisted Dying - a frontier medical practice in Australia.

By any measure, the implementation of Victoria's Assisted Dying legislation has been a wonderful success.

There have been no snafus, no scandals, and no criticisms of medical practice.

The VAD Review Board report to June 2020 with its score of 99% for compliance and general tone provides for confidence in Victoria's successful implementation.

The missing 1% relates to a single, and minor administrative form filling confusion. DWDV is seeking to have this minor system confusion eliminated.

Victoria's successful implementation must have been significant in paving the way for legislative change in WA, for public referendum support in New Zealand, and for potential legislative changes in Tasmania, South Australia and Queensland.

Imagine the consequences if any of the Statewide Voluntary Assisted Dying Care Navigator Service people, (the Navigators), Pharmacists, Doctors, Nurses, Review Board, Health Department or other key people in the complex, and interdependent implementation system hadn't excelled and gone above and beyond.

There was a very strong field of exceptional people considered by the DWDV Board for this year's Rodney Syme Medal. All these people have been outstanding in their contributions to ensuring the successful implementation of Victoria's VAD legislation.

Nevertheless, the DWDV Board was unanimous in selecting the Navigators, Melanie van Diemen and Susan Jury, as the recipients of the year 2020 Rodney Syme Medal.

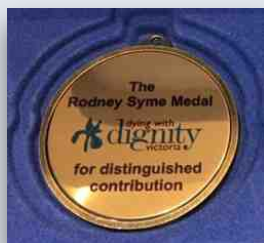
They are the inaugural Navigators working at the Peter McCallum Cancer Centre.

Susan and Melanie created the culture of the Statewide Voluntary Assisted Dying Care Navigator Service - the way things are done by the Navigator Service.

According to the January - June 2020 report of the Voluntary Assisted Dying Review Board, Report of Operations, the Statewide Voluntary Assisted Dying Care Navigator Service had provided support to 613 people seeking information about voluntary assisted dying.



Melanie van Diemen



Susan Jury

The information that community members, medical practitioners and health services can request of Susan and Melanie includes:

- general information about voluntary assisted dying in Victoria
- individualised support and information, either in a face-to-face consultation or by post
- help in connecting people with appropriate medical practitioners and health services
- access to voluntary assisted dying support packages
- holistic advice and follow up on appropriate end of life care services
- education for health services and health practitioners.

I have second-hand experience of their exemplary community service. A close friend of mine asked me for advice to assist her dying sister. I referred my friend to the DWDV Administration Manager, Natalie King. Following discussion, Natalie put my friend in contact with the Navigator Service.

My friend expresses great admiration for the caring help the Navigators provided. She found their dedication and humanity to be outstanding, and of great comfort to her dying sister and her distressed family.

From all accounts, this is not exceptional. It is how the Navigators do their job - every day.



VAD MEDIA WATCH NEWSLETTER

Some members have expressed their desire to receive more information from DWDV on the progress of VAD Legislation from within Victoria, Australia and indeed from around the world. Fortunately, there is a lot of activity to report on. One of our Board Members, Jane Morris, is involved in compiling a weekly newsletter that provides such information.

If you would like to subscribe to this newsletter, "VAD Media Watch", please email Jane at morris.e.jane@gmail.com providing your name and a brief statement about your particular areas of interest.

It is preferred that the newsletter be retained for your interest and not widely distributed. So if you know others who might like to receive it, please invite them to subscribe themselves.

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the gift of
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We are now a Deductible Gift Recipient charity,
which means all donations are now fully tax-deductible.

Your donation will help us to continue successfully
advocating for dignified end-of-life choices for all Australians.

To make a tax deductible donation or find out more, visit
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