

# Dying With Dignity Victoria

Respect the right to choose est. 1974

## ARE WE THERE YET?

BY DR NICK CARR

My youngest is nuts about Ultimate Frisbee. Her team, Ellipsis, just won the Nationals up in Townsville and as a doting parent, I have become a devoted follower and something of a flying disc aficionado. So when I get all excited about “cutting from the stack”, and describing “a great hammer”, it’s easy to



forget that not everyone is as conversant with the territory. Just because I’m passionate and involved doesn’t mean others have come along for the ride.

So, it turns out, it is with the Voluntary Assisted Dying (VAD) legislation. Recently I announced at a meeting of experienced GPs that it was less than two months until VAD becomes lawful in Victoria.

My eyes were aglow with the eager anticipation of their rapturous response, expecting at the very least the odd cry of “Yay!” or a smattering of applause. What I got was “Oh yes, I heard about that – is it going to be legal then?”

In the discussion that ensued it rapidly became clear they knew next to nothing about the law, its implementation and the possible impacts on their own practice. And this was a group of very committed, experienced doctors.

Similarly, I was recently at the Rural Doctors Association conference, on a panel covering palliative care and VAD. Rural practitioners were enthusiastic in discussing the subject, but clearly underinformed about the details.

They were also understandably concerned about where to get information and how to find specialists who will be prepared to be involved. Crucially, they were also concerned about what support will be available to help guide and counsel doctors who do agree to be involved.

Perhaps I shouldn’t have been surprised. It’s been estimated that maybe only 100-150 Victorians in any one year will make use of the new law, so unlike diabetes and hypertension, many of our 6000+ GPs will never have to deal with VAD.

It’s also not lawful yet, and the training has only just become available. It’s therefore

**"Ah yes, I heard about that ...  
When's it going to be legal?"**

understandable that those who haven't been intimately involved in the VAD process haven't yet got the information they need.

**What does this mean for someone suffering from a possibly terminal illness who wants to consider making use of the VAD legislation once it comes in on June 19 this year?**

I believe it means recognising that your GP is highly likely not to be up to speed. Yet. So I believe it's appropriate to start gently nudging the questions. Are they supportive? Are they prepared to find out more? Are they prepared to consider doing the necessary training to become your co-ordinating doctor?

Research shows most doctors are supportive of VAD, but we are also human and as such a bit intimidated by the new and unknown.

So please forgive us if we're a bit ignorant or hesitant at this stage. We'll learn, but we're not quite there yet.

**Dr Rodney Syme says:**

*"I am not surprised by Dr Nick Carr's comments re the medical profession's response. This [VAD] is strange, new and challenging territory for them, despite their inherent empathetic response to the new law.*

*This law was driven by community energy and its implementation must also be driven by this force. Doctors will need to be driven to engage and respond to people's needs, and that will only happen if they are (politely but firmly) asked for engagement and a response. It's up to you and your friends."*

## STOP PRESS!

**From the group that brought you Voluntary Assisted Dying legislation - Dying With Dignity Victoria!**

Finally, some of the people suffering intolerably at the end-of-life will be able to end their lives in dignity, when and where they choose, with loved ones around them if they so choose.

But we recognise not everyone will find the process of accessing the new legislation easy.

That's why on behalf of DWDV, Dr Rodney Syme is offering **personalised support and counselling** for those who seek it.

**If you, or a loved one, needs to speak to someone with over 20 years of experience supporting people at end-of-life, please email us at [office@dwdv.org.au](mailto:office@dwdv.org.au) or call the office on 9874 0503. We'll put you in touch with Dr Syme.**

But we need your help. We need to build a list of GPs who are supportive of VAD - and GPs who are not supportive.

## THIS IS IMPORTANT AND URGENT!

Next time you see your GP, please ask them the following question:

"If I were eligible under the *Voluntary Assisted Dying Act*, would you support me if I wanted to use the process?"

Then, let us know what your GP said - are they supportive or not?

You could also ask them: "Have you already done the VAD training? If not, do you intend to do it soon? "

Please help us to help you, and others.

# VICTORIA DOING IT RIGHT

Four hundred people attended a three-day conference on Voluntary Assisted Dying in May, hosted by the Australian Nursing and Midwifery Foundation.

According to guest speakers from Canada, the four years' time and effort Victoria has invested in detailing the VAD process will prove well worth it.

Conference attendees represented a range of views, including some conscientious objectors. But interestingly, even some of the faith-based organisations present saw VAD as a feasible and caring option at end-of-life.

Concerns were raised about patients being "coerced to die" - but also about patients coercing their doctors regarding eligibility.

Questions were raised about the storage of the medication - who has the key to the locked box?

There were also concerns about possible financial impediments to accessing VAD - travel costs, for example.

From a nurse's perspective, it was recognised that a nurse may conscientiously object but there is still a need for respectful nursing care.

Two state-wide VAD Care Navigators have been appointed, based at the Peter Mac Cancer Centre, with two more to be appointed before the end of the year.

There was discussion about what happens to patients who are deemed ineligible for VAD. Follow up care will be critical and health institutions may need to review their suicide prevention protocols.

Given the strict eligibility criteria, the actual number of people accessing VAD is likely to be small - maybe only 150 a year.

Victorian Voluntary Assisted Dying  
Implementation Conference

8-10 May 2019

But though the number of people directly affected by the full VAD process may be small, many more will be comforted simply knowing the option is available.

There is still a need for training of all health practitioners: how to answer patients' queries about VAD and end-of-life discussions generally?

According to one attendee, many of the anxieties raised were because of unfamiliarity with the information and resources already available on the Dept of Health VAD website.

The easiest way to get this information is to search online for "health.vic", then search for "VAD" in their search box. This lists three areas of information:

- a page that has full information for the community and for health practitioners
- a page that has a summary of frequently asked questions about VAD (including "*How does someone request VAD?*" and "*Can someone with dementia access VAD?*" and "*Can you include VAD in an Advance Care Directive?*")
- a page that describes the role of the VAD Review Board.

# DR RODNEY SYME APPOINTED A PATRON

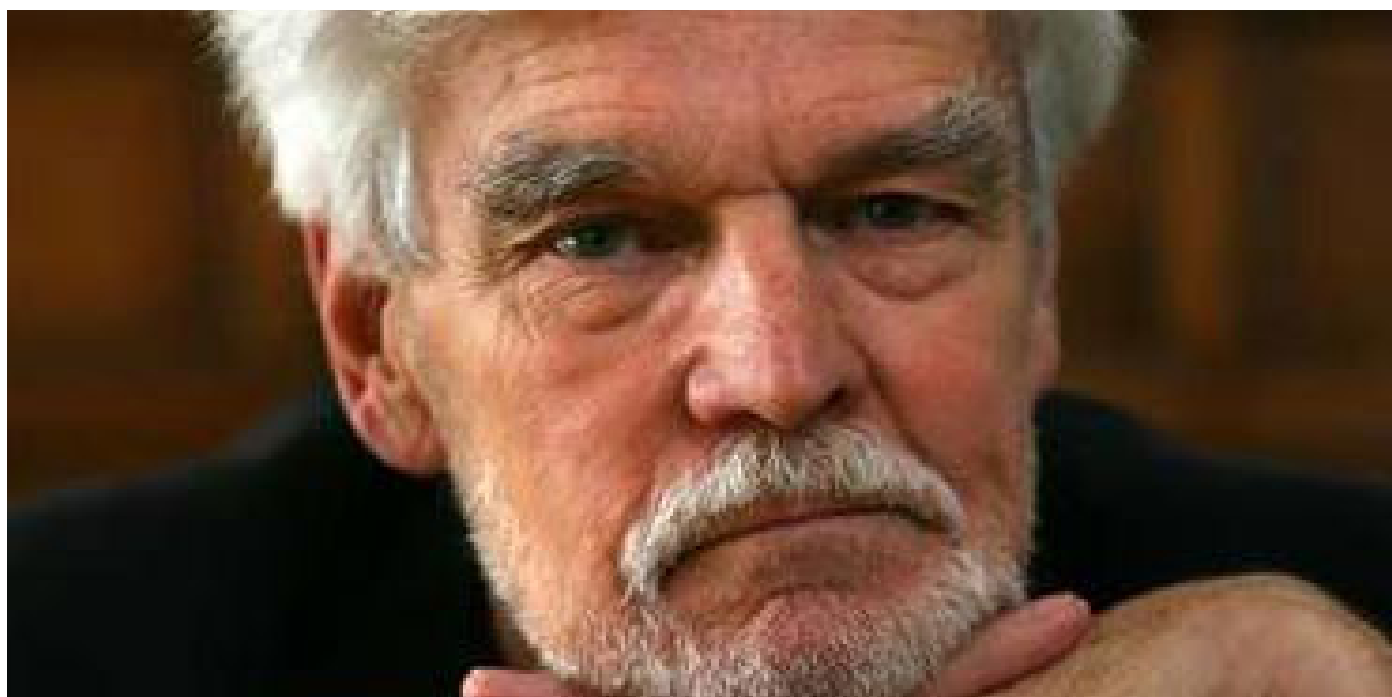
Rodney Syme has made a quite exceptional contribution to advancing the cause of voluntary assisted dying (VAD) law reform and end of life choices generally.

A medical practitioner for over fifty years, Rodney explained in the first of the books he has published (*A Good Death* 2008), that the agonising suffering of a cancer patient many years ago convinced him that people with hopeless and incurable illness should have the right to assistance if their suffering is intolerable and unrelievable.

Since then Rodney has voluntarily devoted

his energies to changing the law to enable the medical right to assistance. He has conducted DWDV information workshops for almost two decades and privately counselled hundreds of patients.

As an act of palliation, he provided many suffering patients with the medication to control the circumstances of their death. He did this discreetly at first but then publicly, putting his own medical career at risk. The relief his assistance provided to these patients was profound, as the testimony of many of them has made clear. In 2016, a



## WANT TO HELP OUT?

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

- **at our workshops - help with setting up and taking down of tables and chairs**
- **at the office - help stuff envelopes from time to time**
- **at home - write letters to the Editor of the major newspapers or your local paper; add positive comments on our facebook page**
- **we also need skills like desktop publishing, facebook advertising, workshop presenting**



VCAT ruling overturning a Medical Board restriction on Rodney's medical licence recognised the palliative nature of his assistance.

Rodney's compelling, responsible, evidence-based public advocacy for VAD law reform has been crucial in informing public opinion and in legislative moves to achieve that reform, notably the Victorian Legislative Council Legal and Social Affairs Committee Inquiry into end-of-life choices, which ultimately culminated in the passage of the Voluntary Assisted Dying Act in the Victorian Parliament in 2017.

During the decades of his advocacy Rodney has served on the board of the international

organisation, the World Federation of Right to Die Societies, and he was President of Dying With Dignity Victoria for ten years. He also served as Chair of Your Last Right and was Vice-President of DWDV until his retirement from the DWDV Board in 2018.

DWDV is proud and delighted that this humane, compassionate man has accepted the appointment as a DWDV Patron.

Rodney joins other DWDV Patrons Rod Mackenzie OAM, who cast the deciding vote that passed the 1988 Medical Treatment Act; former Liberal MP Ian Macphree AO and Julian Burnside AO QC.

## WHAT MEMBERS SAID

With access to the VAD legislation scheduled for 19 June, the Victorian Dying With Dignity movement has achieved a major milestone.

We asked you, our members, where DWDV should now focus time, effort and resources.

According to our survey, the top priorities are:

1. To monitor the implementation of the VAD legislation - what's working and what's not
2. To build the case for extending the VAD legislation.


To achieve the first priority - monitoring implementation, the most important sources of information will be personal experience, from those going through the process and their families, and the providers.

**If you, or anyone you know, is intending to access the VAD process, please consider sharing your experience with us.**

You can do this by calling our office on 9874 0503, or emailing us on [office@dwdiv.org.au](mailto:office@dwdiv.org.au).

As for extending the scope of the legislation: members will be well aware of the compromises that were made to get this legislation passed. DWDV argued for a more compassionate bill, one not so narrow in its eligibility criteria, but we were unsuccessful. We know our opponents will use the "slippery slope" argument if we immediately seek to broaden the VAD Act. So this second priority may have to be a medium term goal.

The successful passage of VAD legislation in Victoria has triggered similar end-of-life inquiries in other states - Western Australia, Queensland, the ACT and perhaps Tasmania and SA. There is potential for their bills to build on the Victorian law, and allow for wider eligibility.



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

# WHAT'S HAPPENING

## WESTERNAUSTRALIA

On 19 March, the WA Health Minister opened up public comments on key issues to be considered in the development of laws to enable VAD in Western Australia. These public consultations, together with a discussion paper released by a Ministerial Expert Panel, is to help with developing a fully informed and workable bill - not to review or debate the arguments for or against VAD.

Importantly, the eligibility conditions proposed for the WA legislation would be less restrictive than those in Victoria. Access could be

**"It's a debate not just for the medical professions but for everyone about how we create a more compassionate and progressive society"**

**Roger Cook, WA Health Minister**

provided to a WA resident for whom death is "reasonably foreseeable" as the outcome of an advanced and progressive terminal illness or disease,



*Campbell Newman and Jocelyn Newman*

chronic illness or disease, or neurodegenerative illness or disease.

## QUEENSLAND

And at the same time, Queenslanders have the chance to have their say. A committee of the Qld parliament is conducting an inquiry into Aged Care, Palliative Care and Voluntary Assisted Dying.

An Issues Paper invites public comment from anyone (not just from Qld) who wish to express views on any aspect of the inquiry.

"We are looking at three of the biggest issues that will affect the lives of all Queenslanders - care when we age, care if we become terminally ill, and having a choice in how and when we die", said the committee Chair. "We have been asked

to gauge public opinion on whether voluntary assisted dying should be allowed in Qld ... whether our state should follow Victoria and implement a system of

**"As Premier, I could have put the issue on the table during our time in office but I didn't. I regret that."**

**Campbell Newman, former Qld Premier**

voluntary assisted dying."

The committee must report to the Qld parliament by 30 November.

## NEW BOARD MEMBER

### DR PETER CHURVEN

I have worked in psychiatry for some 48 years. As a young doctor I found myself more interested in how people coped with life's challenges and suffering than the simple formula for treating their specific illnesses. I was curious how some people coped with pain and personal and social challenges while others became distressed and disordered. I wanted to understand their experiences and what shaped their future course to recovery or disablement. I wanted to be able to help. To this day this remains my professional goal.

I was fortunate in my first year of psychiatric training to be part of an innovative program that used Therapeutic Community principles to transform a traditional medical model admission ward into a social learning environment where all patients and staff were accountable to the community. I learnt the principles and healing potential of respecting and maximising patient autonomy, and participation, and staff accountability in transparent solution-focussed practice. These have been the basis of my

practice ever since.

In post fellowship child psychiatry training I sought training from social workers in family therapy: it seemed to me family therapy embodied similar respectful processes as the therapeutic community.

Of course, these ideas had their seeds in my own life experience. In 1914, Grandpa had the foresight to migrate from Siberia to Australia, in search of a humane and egalitarian society. My father, Greg, a nine year old migrant, became a senior headmaster.

My experience of living and working in varied environments and roles in teaching hospitals, prisons, and senior management have reinforced and expanded my sense of the power of social context and the potential for achieving healing through facilitating healthy family and

community and institutional systems.

As a junior doctor, and later consultant psychiatrist, I worked in child leukaemia teams with children and parents, when the survival rate was about 50%. Over the years I have had the privilege of many conversations with people contemplating or attempting to end their lives. I have been challenged by the medical system's denial of patient self determination in its narrow focus on intensive treatment of pathology like pneumonia or broken bones, even in the elderly and dying. Treatment in the absence of proper appreciation of the whole person and their needs may deny autonomy and prolong suffering, denying a choice to a person on their final journey.

Hence my belated interest in contributing to the cause of Dying with Dignity.





# WORKSHOPS

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

Thanks to years of lobbying, Victorians now have the right to make their future medical treatment wishes *legally enforceable*, and to appoint people who can make sure their wishes are carried out.

## YOUR LIFE, YOUR CHOICE

**Learn how to make sure your wishes are respected and enforced**

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

**Book via the DWDV website [www.dwdv.org.au](http://www.dwdv.org.au)**

- Mon 3 June, 10am at Kew Library
- Mon 1 July, 10am at Kew Library
- Mon 5 August, 6.30pm at Kew Library

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



### PRESIDENT

*Hugh Sarjeant*



### VICE PRESIDENT

*Lesley Vick*



### SECRETARY

*Dr Meredith Doig*



### TREASURER

*Mark Newstead*

### AND THE BOARD...

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

*patience.*

Patience please!

As DWDV moves into a new phase of life (after the successful passage of the VAD legislation), we have had to restructure our office to match our projected income.

As always members are encouraged to call the office to ask questions and seek help, but please bear in mind you may need to leave a message and have us call you back.

The office is now only staffed on a part time basis.



## RENEWAL TIME!

For most DWDV members, 30 June is the time to renew your membership. The easiest way to do this is via the DWDV website. Click on the "Renew membership" button at the top of the page.

If you have any difficulty, please do send an email to [office@dwdv.org.au](mailto:office@dwdv.org.au)