

Dying With Dignity Victoria

Respect the right to choose est. 1974

THE PASSING OF DR RODNEY SYME



Rodney died on the 20th of October, shortly after a stroke. We have lost a leader, a counsellor, and a friend.

Most of you will know Rodney was active in seeking improvements in services for those suffering at end of life. Whilst he was instrumental in achieving important changes to the documentation of options for end-of-life care, his principal objective was to see voluntary assisted dying legislation passed.

From 1974 with the founding of the then Voluntary Euthanasia Society of Victoria (now DWDV), Rodney was energetic, skilful, and utterly fearless in the pursuit of his quest. He wrote, gave interviews, and sought assistance throughout the community. Most striking of all, contrary to the existing law, he risked prosecution and his professional status in stating openly that he had enabled people to end their lives.

There were early failures in the Victorian parliament while attempting to seek legislative change. However, in May 2015 a parliamentary Inquiry was called – in part, as a result of Rodney's work. The notice of it stated-

"... this House requires the Legal and Social Issues Committee to inquire into, consider and report, no later than 31 May 2016, on the need for laws in Victoria to allow citizens to make informed decisions regarding their own end of life choices..."

Rodney was a major force in the ultimate passing of legislation. His work included persuading various politicians to change their position.

Following the passage of the VAD legislation, Rodney was extraordinarily active in providing free counselling for any in need, assisting other states to achieve legislation, seeking improvements in the way the current Victorian legislation is implemented, and continuing to write about matters of concern. Rodney remained a valuable resource for the other states of Australia, and even for other countries.

On Saturday December 4, the Syme family provided for a celebration of the life of Rodney Syme. Hosted by family friends, Shaun and Marina Harris, some of those involved with Rodney's life – particularly in relation to VAD – attended an afternoon function in Hampton with Rodney's son Bruce as MC. As well as offering a chance to meet for some who had not seen each other for a long time, there were memorable speeches from former DWDV president Lesley Vick, Shaun Harris and Go Gentle Australia's Andrew Denton.

The impact of his death has been felt profoundly by so many people within our community and from around the world. Rodney was an extraordinary human and admired for his courage, compassion, integrity and steely determination to help those suffering at the end-of-life.

Following Rodney's death, we have been contacted by DWDV members inquiring about how we intend to honour Rodney's legacy. We suggested to Rodney's family the idea of purchasing a garden seat in Melbourne's Royal Botanic Gardens. The seat would have an attached plaque and would be easily accessible to all.

Rodney loved the Australian bush and we were told he considered the Botanic Gardens to be a 'little bit of country in the city'.

DWDV 2021 AGM REPORT

The 2021 AGM was held via Zoom. We had booked a room at a Boroondara library, in anticipation of a release from lockdown. As it was, we were still constrained by Covid restrictions.



Our FaceBook page has been successful in gathering a growing set of followers.

Vice-president Jane Morris continues her work in the production of MediaWatch, and has had productive engagement with other providers of service to those with end-of-life issues.

With 49 in attendance, and 23 proxies received, we met our required quorum. However, as there were no matters that required a vote, quorum was just for the record.

We were fortunate to have Associate Professor Peter Lange as our guest speaker. Peter is a geriatrician/aged care specialist, and spoke on a range of issues in the provision of VAD.

This year's recipient of the Rodney Syme Medal was Tasmanian MP Mike Gaffney. Mike worked energetically and with great skill to bring forward his private member's bill and to overcome so much of the opposition. Mike was unable to attend, but gave a brief recorded acceptance speech.

A recap of the year made note of the work we had done and some successes in which we would claim to have had a part. These include: the passage of VAD legislation in Tasmania, Queensland, and South Australia; continuing provision of witnesses and contact people; and the new website.

The website now includes some material in foreign languages and information on supportive aged care providers.

We have also been building a record of personal stories, from people who have had involvement with VAD.

We are grateful for support from MLC Stuart Grimley who sought to challenge some of the worst aspects of current Victorian VAD legislation.

A sad note was the passing of Dr Rodney Syme. Rodney has for so long been a major contributor to the development of assisted dying legislation and related services. We are continuing his work, and will also make provisions to preserve his legacy. Our DWDV office continues to provide a first port of call for people in need, and can deal with many enquiries. Rodney's counselling role can be maintained in part by the office, and by our DWDV doctors as circumstances require.

Treasurer Mark Newstead reported that we are able to meet our financial commitments, and expect to be able to do so for the foreseeable future. This fortunate position arises from the extraordinary generosity of our donors, and a helpful sharemarket.

The 2020 Board members were all re-elected unopposed, to their current positions.

We are grateful for the support you all provide to us, and we will continue in pursuit of the DWDV aims. Comments and suggestions are welcome. In the meantime, we wish you all the best for 2022.

WHAT IS AN END-OF-LIFE DOULA?

Doula (pronounced Doo-La) is from the modern Greek language and has come to mean 'a person of service'. An End-of-Life Doula (EOLD) is a non-medical presence for the dying person, as well as their family and loved ones, providing tangible practical supports, education, compassion and resourcing, that enables the individual to have their death unfold in alignment with their wishes. DWDV member, Nicole Grundy, is an End-Of-Life Doula. You can learn more about her and this work on our website:

<https://www.dwdv.org.au/other-resources/what-is-an-end-of-life-doula/>

HONOURING DR RODNEY SYME

We would like to honour Rodney's legacy. He worked tirelessly and selflessly to provide compassionate help to those suffering at the end of life.

He was a major figure in not only the passage of Voluntary Assisted Dying Legislation in Victoria, but also in other Australian states and overseas. Right up until his death, armed with his incredible wealth of knowledge, Rodney strove to help those who continue to die 'bad deaths'.

If you would like to donate to DWDV in Rodney's memory, you can do so via our website dwdv.org.au/donation/ (add 'in memory of Rodney Syme' in the comments box), by posting a cheque to PO Box 743, Kew 3101, or calling the office on 0491 718 632.

Donations to DWDV are tax deductible.

ADVANCING THE RIGHT TO DIE WITH DIGNITY

MEREDITH DOIG



There is a time for all things. In October, the sad news that the wonderful Rodney Syme died after a mercifully short illness.

Among all his many other achievements and high positions, Rodney Syme was a Patron of the Rationalist Society of Australia. The role of Patron of the RSA is offered to persons "*widely recognized as exemplars of rationalist thinking and action over many years*". As Patron, Rodney joined other such luminaries as the Hon. Michael Kirby AC CMG and Prof. the Hon. Gareth Evans AC QC.

In recognition of Rodney's life and contribution as a compassionate, humane and rational human being, the RSA hosted a webinar in November featuring DWDV Board member Dr Nick Carr and DWD NSW president Penny Hackett.

With a record number of registrants, this webinar obviously struck a chord with many people across the nation. A post-webinar survey scored it at 4.5 out of 5, with several respondents saying they would like a future webinar to address the sensitive and difficult topic of dementia and VAD. This was just the topic Rodney was working on for DWDV when he died.

As a practising GP, Nick described what it's like to support patients going through the VAD process. "*What I have to say about a voluntary assisted dying death is that it is so gentle, so peaceful. There's something so beautiful about someone having their wishes granted at the end. I hadn't realised quite how potent the experience is.*" Penny Hackett, taking a brief respite from watching the NSW parliamentary debate, brought everyone up to date with their VAD bill's progress. Two days after the webinar, it passed the lower house 52 to 32 and will now go to the upper house.

Anyone wishing to view this webinar can do so on the RSA Youtube channel:

<https://www.youtube.com/watch?v=unW1qJcdM9w&t=7s>

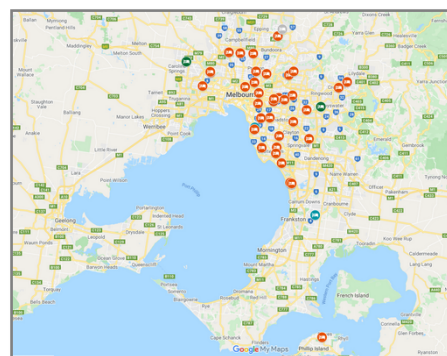
VAD AND AGED CARE FACILITIES

DWDV has commenced a survey of all Aged Care Facilities in Victoria to determine which support VAD and which do not.

We have set up a Google map on our website, showing the location of facilities that have responded and do support VAD.

Work on a comprehensive listing is ongoing and will be updated regularly.

<https://www.dwdv.org.au/find-support/vad-and-aged-care-facilities/>



VAD SUPPORT GROUP

JANE MORRIS



The Support Group for Families and Friends of those who have helped loved ones navigate the VAD process is slowly developing.

DWDV member, End-of-Life Doula, funeral celebrant, and funerary consultant Nicole Grundy has generously offered her time and services to help with the creation and management of this group. Nicole and I have been contacted by individuals who have some incredibly powerful and emotive stories that they so selflessly are willing to share.

Some of these can be seen on our website and it is uplifting, after so many years of stories describing horrific deaths, to finally see how VAD legislation is making such a significant difference to the lives and deaths of some.

We have been overwhelmed at times by the courage and goodwill displayed by these individuals in their desire to share their stories and help others who have faced similar challenges.

Again we emphasise that, if you are aware of anyone who has had VAD experience with their loved one and would like to talk about it, please contact our office. There are some extraordinary people out there willing to talk and listen.

Nicole and I recently completed a short course on grief and bereavement and found it to be extremely informative. We found it led to a lot of discussion and thought pertaining to grief and bereavement in relation to Voluntary Assisted Dying, which obviously has not been looked at in the past.

We look forward to developing this support group next year.



MARIANNE



SHANE



CHERYL



LISA

<https://www.dwdv.org.au/stories/>

NORMALLY I SLEEP WELL

NICK CARR



Normally I sleep well. Overdue tax bills, work stresses, what happened to the goldfish – none of these things keep me from my slumber.

But I tossed and turned the night before I was due to kill someone.

The cause of my restlessness might seem obvious, but it was not, in fact, the moral issue. As a doctor involved in Voluntary Assisted Dying (VAD) care, I had already been present for a number of deaths where patients took a fatal dose of a particular drug. The patients had had the comfort of finally having some control over the end of their lives. Their deaths had been serene to the point of beauty.

But this was going to be my first “practitioner administration”. With an advanced cancer, and unable to swallow, Pete needed me to give him the drugs intravenously. And as a long-standing oncology patient, his veins were shot. I was to arrive at the appointed time with my bag of drugs, his wife and family around him – what if I couldn’t cannulate?

My night was filled with recurring images of scrawny arms, thread like veins and other weird hypnagogic experiences. A steady hand and successful cannulation were not among them.

Dawn broke, I woke sweaty-browed and with a decision made. I rang an anaesthetist mate who I knew lived near Pete. No worries, he said, if you’re in trouble, call me.

The cavalry was on hand.

As I drove to Pete’s after work, a message came through on my phone. “Sorry, stuck in theatre for another 4 hours at least”. The cavalry had just deserted me.

When I arrived, there were at least 10 relatives saying their final farewells; kissing, hugging, taking photos. Eventually they left and it was just Pete, his wife and me. He was in bed, he was warm and - thank goodness - well hydrated. He gave me the final request to proceed. I applied the tourniquet and in the dim glow of his bedside lamp, I began my search. Finally, there it was on his wrist – small, but palpable and visible.

It was only as I tried to put on the gloves that I realised how sweaty my hands were. Fortunately, as I was kneeling by the bed, neither Pete nor his wife could see. I discreetly wiped them on my trousers, all the while keeping up what I hoped was a reassuring patter. Getting gloves on large hands is hard enough anyway, doubly so when they’re damp.

Despite my shaky fumbblings, the cannula obeyed and slid into place. With his wife lying next to him, stroking his forehead and murmuring her goodbyes, I began the process. Seven syringes in all. Within moments Pete was asleep, shortly thereafter his breathing slowed and stopped.

In the family room I met with the relatives and finalised the paperwork with Pete’s wife. Distressed though they were at his parting, his final wish had been granted – to die peacefully at home, in a manner of his choosing, with his family around him. It had been very serene and yes, in its way, beautiful.

That night I slept soundly.



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NEUROPLASTICITY

NICK CARR

Before mobile phones and before personal computers but, curiously, after the moon landing (a feat that seems almost unimaginable today), I was a medical student at Cambridge University. Back then in the 70s we were taught that the adult brain was fixed, unchangeable, the only trajectory one of gradual decline. No new cells were possible, nor any new connections. From the age of 25 onwards it was a one-way street of inevitable decay, and all we could hope for was to minimise the losses as well as possible while sliding slowly into senescence.

Wrong.

We now know the brain remains capable of change throughout life, creating new pathways, connections and even new cells. Sure, it's not quite as elastic in our 60s and 70s as when we were kids - why can I still not touch-type?* - but that's all the more reason why we should optimise the possibilities.

This new understanding is called neuroplasticity, and it has inevitably spawned a whole industry of brain training games and apps. Sadly there is as yet no proof that any of these guard against dementia - the most that has been shown is that people get better at doing the game/app they use, but not at other unrelated tests of memory or performance. That's not to say don't try them. If it's fun and pushes your brain somewhere new, there may be benefits we haven't yet proven.

Here's my personal, unproven theory about what we should be doing. My metaphor for the brain is a jungle through which we create paths. As we age, the jungle threatens to take over, and if all we do is keep going down the same paths, the jungle just gets thicker and more impenetrable elsewhere. And because of this, it becomes easier just to stay on the familiar paths; which is in fact exactly what we tend to do as we age. We seek the comfort of routines, friends/media/experiences that do not challenge us too much. We prefer options that don't over-stress our increasingly inelastic brains. Which may be fine if we're comfortable with decline. If not, maybe we need to get out the machete and thrash new paths, trample down the undergrowth and forge fresh side branches.

What does this mean in practice? I believe it means doing things that we don't really want to do. In short, things that are uncomfortable. Sure, Sudoku and cryptic crosswords are great, but if you've always done them, they're comfortable and maybe just keeping the same old paths clear - the jungle meanwhile encroaching all around. What about taking up the violin, learning to tango or memorising a chunk of Hamlet? If you're right handed, have you ever tried brushing your teeth (or shaving, or wiping your backside) with your left hand?

Going abroad? Learn the language.

The Voluntary Assisted Dying bill specifically excludes assisted dying if we have dementia. So it is all the more important to do everything in our power to prevent it, to ward off the jungle of plaques and tangles so familiar to neuropathologists. Embracing the concept of neuroplasticity is perhaps one way. There may not be any science to it as yet, but there can't be too many harms that come from starting to learn Swahili - while brushing your teeth with the wrong hand.

**Perhaps because I've never made a concerted effort to learn. I was too dismayed to try after watching my then 12-year-old daughter touch typing. I said to her, "When did you learn to do that?" She gave me the kind of withering, disparaging look that can only pass between child and parent as she replied, "Its easy, Dad, you just do it". If only...*



A TRIBUTE TO DR RODNEY SYME

SHANE SMITH (DWDV MEMBER)

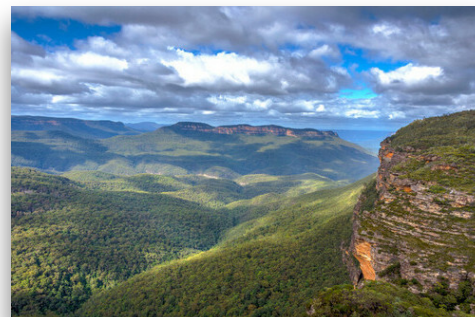
By all accounts, Rodney was a stranger to me, yet in just a couple of conversations, he had more impact than many people I have known for most of my life!

When I find myself in these moments and particularly when I am meditating and processing these things, I often visualize myself atop a mountain peak scanning a vast and infinite mountain range.

I can see all the highs and lows. Some of the valleys, deep and dark, others - full of sunshine and light! Scattered across various peaks, I see images of those who have touched my life - both good and bad.

On one such peak, I see my sister, no longer suffering, full of peace and smiling. Nearby, I see Rodney, gazing down. His warm smile - his kind eyes, full of love and compassion, with his hand gently reaching out to comfort her!

As he did for me - in the living world!



ETHICAL RIGHTS VOLUNTARY ASSISTED DYING SURVEY

Ethical Rights surveyed voluntary assisted dying advocates throughout 2020–2021 on many of the ethical issues, policy/regulatory issues and individual preferences that arise in the public debate on voluntary assisted dying (VAD, also voluntary euthanasia, medical aid in dying, physician-assisted suicide).

As VAD advocates, their views on what VAD regulatory systems should look like, summarised as key messages in the Summary Report, are highly relevant.

A total of 1640 respondents from 31 countries responded to the survey.

Respondents' views were sought on many issues including, for example, whether VAD should be a right for all adults, whether being terminally ill should be an eligibility criterion (necessary condition) for regulated VAD, and what ought to be the role of doctors, if any, in VAD.

The survey also expands the VAD debate through obtaining respondents' views on challenging issues, such as whether there are any attributes that could make a person automatically ineligible for voluntary assisted dying, such as being a convicted criminal, being a child, being pregnant, or having dementia.

Their website offers four pdf documents for download, the survey's Summary Report, Results, Supplementary Material and Survey Questions respectively.

<https://www.ethicalrights.com/surveys>



NEWS FROM AUSTRALIA...

New South Wales

Wonderful news was received from NSW on Friday November 26, with the successful passage of the *NSW Voluntary Assisted Dying Act, 2021* through the Lower House.

After many delays, including the cessation of Parliamentary sittings due to Covid, turmoil within the Government that included the resignation of the Premier Gladys Berejiklian and some key VAD supportive MPs, the Bill passed 52 votes to 32 votes.

The bill was introduced into Parliament by Independent Alex Greenwich and was co-sponsored by 28 MPs. Both major parties were eventually allowed a conscience vote, with one senior Liberal MP indicating that he would resign from the front bench had Liberal MPs not been provided with a conscience vote. One hundred and sixty-seven amendments were added but most of these were voted against. It was stated that if the bill passed the Lower House, it would be sent to the Law and Justice Committee for review.

Fortunately, the Bill was sent before the Lower House result and an inquiry commenced immediately. The Committee must table its report by the first day of Parliament next year and we will see debate commence in the Upper House, in early February.

We sincerely congratulate those MPs who worked so hard to advocate for the Bill, the entire DWDNSW team, especially Penny Hackett and Shayne Higson and of course Andrew Denton and his Go Gentle Australia team. Despite setback after setback, their campaign was extraordinary and obviously extremely successful.

In a very touching and emotional moment, Alex Greenwich, sponsor of the Bill, dedicated the passage of the VAD legislation to Shayne Higson's mother, who died a horrific death, in 2012, from a brain tumour. It was a beautiful gesture. We eagerly await news from the NSW Upper House early next year.

Other Australian News

In other Australian news, it was reported 50 Western Australians have ended their lives using VAD law and that 211 people had made first requests, with 125 first assessments having been completed. These deaths had involved 43 practitioner VAD providers. One hundred and sixty practitioners are said to have enrolled for VAD training.

Meanwhile South Australians eagerly await the announcement of a date on which VAD may be implemented. Suggestions have been made that the implementation phase could be as long as two years.

In Tasmania, expressions of interest regarding five positions in the recently announced "Voluntary Assisted Dying Commission" have been called for.

Earlier in October the Federal Attorney-General Michaelia Cash reiterated her refusal to consider overturning the ban on the territories' rights to debate VAD laws. However, a few weeks later, the Federal Labor Party announced that, should they win the next election, they will facilitate a vote on Territory rights. A bill, introduced by NT Senator, Sam McMahon, is currently before Parliament, but is said to be poorly drafted and controversially does not include an appeal for the rights of the ACT.



... AND AROUND THE WORLD

Rest of the World

There is still a lot of VAD activity and advocacy occurring in all corners of the world.

As from November 7, 2021, Assisted Dying became legal in New Zealand.

The Portuguese parliament passed an amended assisted dying bill, 138 to 84 votes. However, Portugal's President has, for a second time, refused to sign a parliamentary sanctioned bill. The bill has been shelved until a new parliament and government are formed early next year.

Austria's federal government has submitted a draft law to make assisted suicide for seriously ill adults legal. In October we saw the *Assisted Dying Bill* pass the second reading stage unopposed in the House of Lords. The sponsor of the Bill, Baroness Molly Meacher, has recently announced that the Royal College of Surgeons is reviewing its position on VAD. It is the only medical college not to have moved from opposed to neutral.

Meanwhile, September saw a new push for assisted dying in Scotland when Liam McArthur MSP launched a consultation on the *Assisted Dying for Terminally Ill Adults (Scotland) Bill* at Holyrood.

In Jersey a Citizens Jury voted to introduce assisted dying and a recently held vote resulted in Jersey's assembly voting in principle to introduce a VAD law.

Finally, in Ireland last year TD (Teachta Dála, member of the Lower House), Gino Kelly, introduced a *Dying with Dignity Bill* which was later described as poorly drafted by the Oireachtas Justice Committee. He has since redrafted the Bill and is said to have modelled it on Queensland Legislation. 'The Sunday Times' has recently announced the launch of a campaign to legalise assisted dying in Ireland and in January a special committee on Voluntary Assisted Dying will be set up.

2022 will no doubt prove to be just as exciting and busy as previous years in the VAD world.



FATAL FRAUD

A 'film about a film', *Fatal Fraud* is a case study about techniques used by opponents against evidence-based public policy initiatives. In this film, Andrew Denton explains with the help of leading experts how emotional manipulation, fear, framing and omission are deployed to sow Fear, Uncertainty and Doubt in the minds of legislators and the public.

For links to this film .. and more ... visit the list of *Books Films and Podcasts* under *Other Resources* on our website:

<https://www.dwdv.org.au/other-resources/books-films-and-podcasts/>



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