

Newsletter #196, Jun 2022

PRESIDENT'S REPORT

Our congratulations to all involved in the success in New South Wales, but especially the DWDNSW executive, who have fought so hard and for so long. Press reports included "Previous attempts to pass similar legislation were blocked in the NSW Parliament in 2017 by one vote, but the most recent bill appeared to have widespread support, with 28 co-sponsors across all parties – reportedly the highest number of any bill in Australian parliamentary history". Whilst a triumph, it had always appeared to be highly likely – the shift in thinking in Australia has been clear for several years.

With now around just 2.7% of Australia's population without assisted dying legislation, former Prime Minister, Scott Morrison, decided to announce just before the election that a Coalition government would not seek to overturn the law that bans the territories from legislating on voluntary assisted dying. Throughout recent years, and particularly since the Victorian Inquiry of 2015, so much of the conservative side of politics has appeared to be in thrall to the opponents of assisted dying.

However, with the newly elected Prime Minister, Anthony Albanese, having promised to make a vote to restore Territory rights to legislate on voluntary euthanasia a priority, it would seem the ban will be lifted before too long. Further, Kristy McBain has indicated her strong support – see the article by VP Jane Morris on National News. It may then be that the Northern Territory can restore what it lost in 1997 - or an equivalent. Both the Northern Territory and the ACT may benefit from the combined experience of the various state legislatures since the passage of legislation in Victoria in 2017. The inclusion in federal



by Hugh Sarjeant

parliament of a much-expanded crossbench might perhaps assist in getting a better standard of debate. So often in Australian politics, with voting based purely on party lines, we have had not so much a democracy as a dictatorship from the leadership of the party in power.

In Victoria, we are now at the 3-year mark after implementation of our Voluntary Assisted Dying laws. Whilst we can take pleasure in the overall success, with the very high levels of compliance, there is much still to be done. The VAD Navigators have been magnificent, and those doctors who have pitched in have done excellent work, but there is still a rather low level of support from the medical profession as a whole.

Also, we are seeking to enhance our level of service, because so many in the community remain unaware of their rights. We are also developing the provision of data on support from industry, and seeking to enable other forms of assistance to the community.



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NIA-APERSONAL REFLECTION

In life, some of us are fortunate enough to meet a person that profoundly affects the way we live and helps shape the path that lies ahead. Nia Sims was one of such special people whom I feel so privileged to have met.



When I first spoke with Nia, any initial notion I had of pity for her immediately evaporated. Nia exuded strength. This, I thought, was a woman in control; she knew exactly what she wanted and set out exuberantly to achieve whatever she had set her mind upon. Like myself, Nia was a fierce advocate of VAD; she had witnessed the horrific death of her beloved father. However, Nia also had another reason to immerse herself in the VAD campaign so earnestly; she herself suffered from a terminal illness. She did not let her illness characterize her, nor did she dwell on what she was unable to do. Instead, Nia strove to achieve goals beyond the confines of her restrictive medical parameters and concentrated on what she could achieve by reaching out.

We sat through the entire parliamentary debate and, despite Nia's fierce independence, she would quietly acknowledge her physical limitations and would ask on occasion for assistance. As I was a former nurse myself, she sought my help. In all honesty I did very little for Nia. However she was always most insistent that, wherever we went, her "Nurse Jane" accompany her. As a result, I sat alongside Nia in prime viewing positions in the Parliamentary gallery and was always assured of a front row seat at any conference or meeting!

I intimately saw the struggles Nia faced every minute of the day and marvelled at her stoicism and determination to squeeze as much as she could into every minute of her life. The only time I ever heard Nia complain was a time when she was away on a beach holiday. She was talking with me on the phone, sitting on a veranda, watching the world go by. Suddenly I could hear the screams of two children fighting. They were arguing over whose turn it was to walk their dog; neither was enthusiastic to do so. It was then Nia confided that it



by Jane Morris

was on such occasions she felt very sad and frustrated. "I would give anything to be able to walk a dog" she said. I shall always think of Nia as I walk my dog and try and treasure every step I take.

Nia made an indelible impression upon everyone who met her. She was clever, an expressive writer, wise, and pragmatic - and always her beautiful soul shone through. She will be remembered, not for her illness, but her strength, her boundless resilience, her infectious optimism, and most of all her joie de vivre.

Nia, you enriched so many of our lives. You will never ever be forgotten. Rest peacefully.



Rodney Syme with Nia



Nia with Jane Morris

SOCIAL MEDIA & PERSONAL STORIES



As we have mentioned before, stories about the evils of social media persistently abound. However, social media for many people can prove to be a "meeting place" where they can express views and relate personal stories with 'relative' anonymity.

Through our Facebook and Twitter sites, DWDV has connected with some incredible individuals, who have selflessly shared their stories and engaged with others, often subjected to similar end-of-life experiences.

We have placed some of these stories on our website, and have been amazed at the amount and level of conversation they have initiated. As we all know, there are some people who regard their own personal story as having little value but, after having related it to others, realize the power of their shared experience and the opportunity to provide support and connect with others. It is also through social media discussion that DWDV may be initially alerted to problems encountered during the VAD process, issues with the execution of Advance Care Directives, or other pressing end-of-life concerns. It is extremely important we are made aware of these, as a major role of ours is to ensure the efficacy of the end-of-life legislations that we strove so hard to achieve.

Of course, if you are not a fan of social media, we welcome you to contact us with any stories/issues you would like to share. You may email us or submit your story directly through our website; see *Personal Stories*.

To those who have reached out, an enormous thank you. We feel extremely privileged and honoured to have had your stories shared with us. You are all truly amazing and inspirational individuals.

ACD TRANSLATIONS

Dying With Dignity Victoria (DWDV) now offers translated versions of our suggested form for Advance Care Directives as a guide.

The majority have been automatically translated by "Google Translate" and therefore may not be an accurate translation. In addition, the legislation requires the completion of documents in the English version.

We hope they will nevertheless be of assistsance to non-English speakers.

You will find them on our website under Find Support > Advance Care Directives.

DWDV does not offer advice on the options you choose – this is for you to decide.



RODNEY'SLASTCAMP

Ever since we met the Syme Family over 35 years ago, camping together has been a twice-yearly ritual. My husband and sons were a constant. I must admit that I have been more absent than present over the past decade, however, this year was going to be special and I wasn't about to miss it.

Rodney's children- Robin, Bruce and Megan -their partners , most of the grandchildren and three of us made the special trip over the border to Rodney's beloved Gulpa Creek in the Murray Valley National Park. Bruce had arrived earlier and secured a stunning and peaceful spot on a bend of the creek. We slept in 4WD roof-top pop ups and swags under the plentiful stars. A far cry from the leaky tents, forgotten flies and missing poles of years gone by.



Much has changed over the years. Not only have our creature comforts increased exponentially with the introduction of trestle tables, shade structures, hammocks and portable refrigeration etc; our food is now positively gourmet! I don't think I'll ever forget my first experience of foraging through Rodney's old cardboard box of camp food: most of it in rusty tins, out of date by several years. He insisted that flyblown rabbit would be ok to eat after hanging in the open for a few days. With the introduction of blueberry pancakes for breakfast, slowly roasted lamb buried in the coals of a fire pit for dinner and freshly poached quinces for dessert, we were able to leave the gastro meds at home and be well nourished enough to enjoy the camp.

Although he certainly enjoyed the comforts on camp, they didn't matter to Rodney. He was always very happy as long as he had his binoculars, plentiful birdlife, a good campfire, good company, a campfire debate and a cheeky red or two. So, on the Friday morning, accompanied by birdsong and a Syme family favourite, Albinoni: Adagio in G minor/Pachelbel: Canon, it was under the magnificent towering red gums, and into the fast



by Marina Harris

flowing creek that some of Rodney's ashes were sent downstream by his son-in-law, Carey, in a lovingly fashioned log, replete with tea lights and pretty wildflowers. We drank champagne and we hugged and we cried. Later some friends joined the camp and as our numbers swelled a little, the mood became less sombre. We played Bocce and board games and shared our many stories of Rodney.

One Easter camp ritual was the floating device competition. They needed to be fashioned from found materials (from the camp site) and needed to float down the creek (holding a human) for as long as possible. It was always fantastic fun, especially when our children were young. However it became very competitive with much cheating as unnamed people "found" floating objects that had clearly been smuggled into camp. It had to stop. Thankfully, another ritual, The Easter Art Competition, has survived. The creation of art from found objects. Rodney used to get very involved in this. It has become quite a competition.



RODNEY'SLAST CAMP(CONT)

My husband Shaun had been thinking about his creation for some time. He wanted to create something special to honour Rodney. He'd be off on walks collecting sticks and twigs and then he'd disappear. What he made was a gigantic nest. (A homage to Nils-Udo, but on a much smaller scale.)

It was there, on the Saturday, inside the nest that we rested more of Rodney's ashes. The inner nest was lined with soft grasses. Rodney's favourite camp cup, more wildflowers and a special rock from Yandoit (from Rodney and Meg's last home together) were laid inside.

We will return and visit Rodney over the coming years. We will remember him and, of course, share a cheeky red with him. We believe that Rodney will be very happy there, under the mighty gums at his beloved Gulpa Creek serenaded by birdsong and surrounded by some beautiful artworks created by his family and friends.

His grandson's Kangaroo was the winner.

NEW DWDV BOARD MEMBER

We are delighted to welcome Associate Professor Peter Lange as a new member of the DWDV Board. His background and experience will be a wonderful asset to support us in our work and in achieving our aims as an organisation.

Peter Lange completed a Bachelor of Science degree at the University of Queensland, majoring in physiology and pharmacology. He then completed postgraduate medicine, obtaining an MBBS, internship and early years of training in Queensland. He came to Melbourne in 2005 where he completed physician and geriatrics advanced training at the Royal Melbourne Hospital.

He commenced work both in the General Medicine and Geriatrics departments in 2010. In 2012 he was appointed head of the Assessment and Planning Unit at RMH, later renamed the Acute Medical Unit where he was head of unit until stepping down to pursue research in 2021.

In 2016 he took up a PhD with the topic "Delirium in Hospitalised Elderly; changing the Natural History" at the University of Melbourne, representing the formalisation of a research interest in delirium.

In 2019 he was appointed Honorary Clinical Associate Professor of the University of Melbourne.

DWDV ANNUAL GENERAL MEETING

Saturday November 12th @ 2:00 pm Hawthorn Library

Further details will be forwarded to all members closer to the date.





A/Prof Peter Lange



NEWSFROM AUSTRALIA ...

As referred to in the "President's report" we were elated to finally see the passage of VAD legislation in the NSW parliament. Advocates of VAD threw everything into their campaigns, including very effective full-page advertisements in local papers, placed by DWDNSW and Go Gentle Australia. This was set against a backdrop of staunch and often vitriolic arguments posed by the opposition.



In an unprecedented event, Lord Carey, former Archbishop of Canterbury (UK) wrote to every NSW Upper House MP to urge them to pass the bill and said that attempts to deny VAD to residents of aged-care homes run by Catholic and Anglican bodies would be "cruel, monstrous, unethical and un-Christian."

In the aftermath of the passage of the legislation, the NSW Premier and Opposition leader, both of Catholic faith, were condemned by the Catholic church for not having taken a firm stance against the VAD bill on the Parliamentary floor. Furthermore, a Catholic newsletter reported a comparison between VAD and the Holocaust which elicited an immediate rebuke from Jewish community leaders.

Prior to the Federal election, the then current Prime Minister Morrison announced that, was his government to be returned, he had no intention of allowing the ban on the territories from debating VAD legislation to be overturned. The then Opposition Leader, Anthony Albanese, had previously promised that he would allow a vote in the Parliament to overturn this discriminatory legislation.

Less than 3 weeks after the election, newly appointed Minister for The Territories, Kristy McBain, announced that she will support a private member's bill to allow a conscience vote for all Labor MPs on the repeal of the Federal Legislation. David Pocock, Independent ACT Senate candidate, also pledged during his election campaign that he would move a private Senator's bill to restore the ACT's right to legislate for VAD, should he be elected. His campaign was successful and he made history, becoming the first independent senator for a territory.

South Australians continue to be extremely frustrated as they await the announcement of a date on which VAD can be formally implemented, hopefully earlier than the stated March 2023 date.

It was great to see a five-page article on VAD in the April edition of 'The Australian Women's Weekly'.

A statement from the anti-VAD organization, HOPE, released during the NSW VAD Parliamentary debate -"The work of dismantling these laws, state by state, begins today. We will not stop until we have overturned them all, restoring our country to one that values every human being as possessing inalienable dignity, value and worth. We will not stand by and allow a culture of death to prevail in this nation".

We can never become complacent.

.. AND AROUND THE WORLD

Canada

There has been a consistent deluge of news from Canada as they attempt to expand MAiD eligibility criteria. They have faced some fierce opposition to the intended inclusion, in March 2023, of individuals seeking MAiD based solely on a mental health illness. This is despite a final report by an expert panel who concluded that existing safeguards and eligibility criteria were satisfactory. There have been reported cases of individuals with disabilities and health issues who have found it easier to access MAiD than receive financial support for specialized living conditions and/or treatment. Such cases have led to sensational headlines such as "Why is Canada euthanising the poor?" A proposed bill in Quebec that would allow those suffering from Alzheimer's disease to access MAiD by providing consent, before they are deemed incompetent, has been put on hold and will be discussed at the next Parliamentary session.

Belgium

Belgium has marked two decades since Assisted Dying was legalized. Reports state that it is one step closer to allowing advance requests for dementia patients to access assisted death.

Colombia

The constitutional court of Colombia has legalized Physician Assisted Suicide, decriminalizing PAS for people who suffer from severe health conditions that patients consider a threat to their dignity.

Cyprus

A British man who assisted his terminally ill wife to die will be tried for murder, despite his British lawyers applying to have the charge downgraded to assisting a suicide.

France

Prior to the recent April French election, Emmanuel Macron stated his support for assisted dying and commented that he favours the Belgian model.

Korea

The results of a recent poll have indicated that more than 76% of Koreans support legalizing euthanasia, or physician-assisted suicide.

The Netherlands

It is also two decades since Assisted Dying was legalised in the Netherlands.

New Zealand

It has been six months since the End-of-Life Choice Act was implemented. Ministry of Health data showed that as of May 1, 2022, ninety-two people had chosen to have an assisted death and overall, 267 applications had been made.

Peru

Peru has become the second Latin American country, after Colombia, to deliberate a VAD case, in their courts, after a 2021 Lima Court ruling that exempted a woman, with a terminal muscular disease, from the national ban on assisted dying.

Portugal

For the third time in just over a year, parliament has voted in favour of allowing assisted dying. Presidential approval is required for the bill to become law. As we have seen with previous attempts, the President can block the legislation or send it to the Constitutional Court for vetting.

United Kingdom

Baroness Meacher, who introduced an Assisted Dying Bill into the House of Lords last year, believes that a majority of MPs in the House of Commons are in favour of a change in assisted dying legislation, and she expects a change in law at some stage over the next few years. Despite the Jersey States Assembly agreeing in principle to allowing assisted dying, making it the first place in the British Isles to do so, legislation will not be implemented until at least 2024. An assisted dying bill was successfully introduced into the Isle of Man's parliament, 22 to 2 votes. A public consultation is expected to be held over the summer and a draft bill should be available by the end of the year.

United States

Oregon has ended its MAiD eligibility criteria requiring MAiD candidates to be residents of the state. In Hawaii MAID was legalized 3 years ago. However, it appears that, due to a shortage of trained providers and long mandatory waiting periods, people are dying before they have the chance to access medication. Unfortunately, a recently introduced bill intended to circumvent these obstacles, failed to pass.

Uruguay

Parliament began to debate assisted dying legislation in May.



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CAN YOUHELP US WITH A DONATION?



We are deeply appreciative of the amazing work done by all our volunteers, but we also rely on the generosity of donors and other benefactors to help us support the right to individual end-of-life choices through voluntary assisted dying, advocate for improvements to current laws and provide support and education for individuals, organisations and communities.

Would you consider making a donation to DWDV?

You can do so through our secure online form here: https://www.dwdv.org.au/donation/ (All online donations are processed securely using Stripe.)

Alternatively, contact our office for details to make a payment by direct bank transfer or cheque.

We are a Deductible Recipient Chariity, so all donations over \$2 are tax deductible.