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ROY MORGAN RESEARCH POLL 2017

85% OF AUSTRALIANS SUPPORT VOLUNTARY ASSISTED DYING

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President's message



If we thought 2018 was going to be a quiet year then we were mistaken. The issue of voluntary assisted dying (VAD) is a hot topic across Australia and around the world. There has been a great deal of media and many developments to keep abreast of, some exciting and some worrying.

On the positive front, the US State of Hawaii passed a VAD law in March with a resounding majority (see page 16) and there are Parliamentary Inquiries into end-of-life choices underway in Western Australia, the Australian Capital Territory and New Zealand. Senator Richard Di Natale has said that the Greens plan to renew their push for Australian territories to be able to legislate for VAD, and interesting rumblings are coming from Tasmania and Queensland. (See pages 13 - 14.)

Whilst there is still significant opposition to VAD by medical groups in the US, ten state chapters of the American Medical Association have now switched from 'opposed' to 'neutral', along with some specialist groups. The American Medical Association Council has spent two years reviewing the group's stance on VAD and recommended continued opposition. However, it is very significant that at the Annual Conference in June 56% of delegates voted not to accept the Council's report and to send it back for further review.

We will be interested to see if the newly elected Australian Medical Association (AMA) President, Dr Tony Bartone, takes a less strident stance against VAD than his predecessor, Dr Michael Gannon. The AMA's policy on VAD states that "laws in relation to euthanasia and physician assisted suicide are ultimately a matter for society and government." It was great to see Professor Brian Owler, past AMA President, receive recognition in the 2018 Queen's Birthday Honours List (see page 5 for details).

In Europe, there has been a lot of interest in the VAD bill presented to the Parliament of Guernsey. Whilst the bill was defeated after a three-day

debate it generated awareness and has inspired Jersey (the largest of the UK Channel Islands) to campaign for VAD. The Portuguese Parliament also debated a VAD bill, which was defeated by only a slim majority. This was a very encouraging result for a predominantly Catholic country. Meanwhile, we keenly await the decision of the UK Court of Appeal in Noel Conway's judicial appeal heard in May 2018 (see page 15).

On the negative front, the VAD laws in California were ruled unconstitutional in May after right-to-life and associated medical groups took court action. We understand that this is likely to be overturned on appeal, but it is a shocking development and reminds us that even where these laws are passed the opponents will continue to fight to have them reversed. (See pages 15 and 16 for all the international news).

The Californian situation is important in the context of the recently passed Victorian laws. There is some pressure on the Victorian Liberal Party to overturn the laws if they win government in November. Recent articles in *The Age* have pointed to the increasing power of the religious conservative wing of the Victorian Liberals. To our immense relief, their leader, Matthew Guy, has confirmed that he will not seek to overturn the laws. However, we must be vigilant to ensure that laws supported by the majority of the community are not obstructed by those who ultimately oppose them purely on ideological and religious grounds.

On a brighter note, we welcome a new member to our Board, Debbie Ditchfield (see page 5). The Board are busy implementing a new software platform to manage our members and supporters and improve our ability to communicate with you and to campaign much more effectively.

The world's media has been abuzz with the story of Professor David Goodall and his journey to Switzerland (at age 104) to take advantage of their VAD laws. While he would not have qualified for assistance under the laws recently passed in Victoria his situation raises some uncomfortable issues regarding increasing suicide rates in the elderly and terminally ill, as highlighted in my *Sydney Morning Herald* opinion piece (reproduced on pages 4). Goodall's story has prompted a lot of interest in the Swiss laws and their application to foreigners, so we have included an 'explainer' in this issue (see pages 12 and 13).

We intend to ask all political parties registered to stand at the NSW election on 23 March 2019 about their policies and position on VAD. We will provide you with this information closer to the election.

The Voluntary Euthanasia Party (the VEP) are gearing up for the NSW election and have announced their top two candidates for the Upper House. They are Shayne Higson, DWD NSW Vice President, and Paul Gabrielides, the husband of the late Annie Gabrielides, who was the ‘face’ of our NSW campaign during 2017 for the *Voluntary Assisted Dying Bill*. The VEP’s campaign in the lead-up to the NSW election will help us draw public attention to the need for laws in Australia to permit VAD (see page 8).

It is well known that the majority of Christians support VAD despite the staunch opposition from the church hierarchy. A new survey has confirmed

that the theological stance does not reflect the ‘views from the pews’. See the report on page 7 from Ian Wood of the Christians Supporting Choice for Voluntary Euthanasia.

In the same way as the churches are out of step with their congregation, so too are many MPs out of step with the wishes of the community.

And finally, in March we farewelled Professor Stephen Hawking, who lived for more than fifty years with Motor Neuron Disease, much of that time profoundly disabled. Professor Hawking changed his view on voluntary assisted dying in the later years of his life and became a compelling advocate for the right to choose.

Penny Hackett

President, DWD NSW

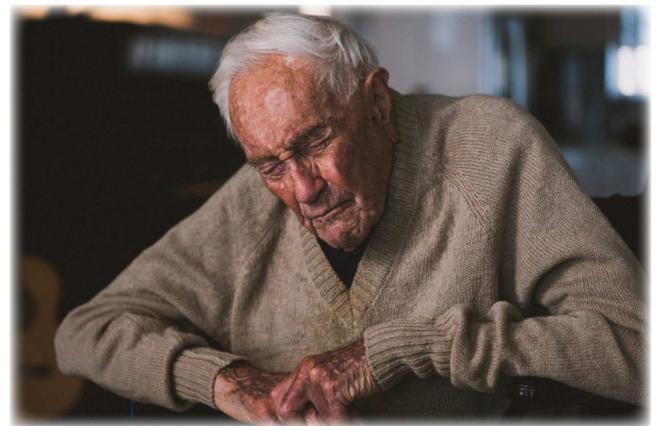
Professor David Goodall’s story

Local and international media were fascinated by the story of the 104 year old scientist from Western Australia who travelled to Switzerland to end his life in May 2018.

Professor David Goodall was as an academic, researcher and author in the area of plant ecology and natural resources management, producing more than 100 research papers and earning three doctorates in a career that spanned 75 years. While his mind was still sharp he was deteriorating physically and had tried unsuccessfully to take his own life prior to making the decision that he would travel to Switzerland to take advantage of their voluntary assisted dying (VAD) laws.

On 10 May 2018 Professor Goodall, surrounded by members of his family, died “peacefully” from an infusion of Nembutal at the Lifecircle Clinic in Basel, Switzerland. The following day the *Sydney Morning Herald* published an opinion piece by Penny Hackett, DWD NSW President (see page 4).

An on-line article referred to comments by Dr Rodney Syme, the Vice President of Dying with Dignity Victoria, about Professor Goodall’s death: “while Goodall wasn’t diagnosed with a



Professor David Goodall, aged 104.
Photo by Hugh Sando ABC News

terminal illness Dr Syme says that someone at 104 years of age is effectively terminal due to huge degeneration of the body systems”. Dr Syme was quoted as saying “his brain was still functioning very well but his body was physically giving up on him” (published by dscribe.net.au on 24 May).

On the day before his death, Goodall had told a group of reporters: “Even up to the age of 90 I was enjoying life, but not now... My life has been rather poor for the past year or so and I’m very happy to end it” (*ABC News* 6 May 2018).

Goodall’s story has prompted discussion of end-of-life options for Australians who are able to travel. These options are expensive and not available to everyone who wishes to have VAD. Opting for VAD overseas often means that the suffering person dies earlier than if VAD was available in Australia.

DWD NSW campaigns for VAD laws to allow residents of NSW who are terminally or incurably ill and experiencing unrelievable suffering the option of dying peacefully, surrounded by their friends and family at the time and place of their choosing.

To answer some of the questions we get from our members, we have provided an “explainer” about the laws in Switzerland and the organisations

which offer assisted dying services to those who meet their strict criteria, including foreigners (see pages 12 and 13).

Thank you to our member, Andre Mauchle, for writing the emotional and informative story of his wife, Anne, who chose an assisted death in Switzerland last year (see pages 11 and 12).

Following is an opinion piece written by Penny Hackett, Dying with Dignity NSW President, which was published in the *Sydney Morning Herald* on 11 May 2018.

David Goodall’s story forces us to confront uncomfortable truths

The journey of 104 year old Professor David Goodall to end his life in a Swiss clinic has resonated around the world. He would not have met the criteria for assisting dying laws for the terminally ill recently passed in Victoria and under consideration in other states. However, his story forces us to confront uncomfortable issues surrounding death and dying and the genuine fear that many ill and elderly people hold as they approach the end of their lives.

Modern medical practice is very focused on curing people but struggles to confront the suffering where death is inevitable and unavoidable. Suffering is not just about pain and physical symptoms. For many, issues such as loss of dignity, independence, physical immobility and inability to communicate with loved ones can have devastating effects.

Even with the best palliative care, many people still experience unbearable physical and mental suffering as they approach death.

Professor Goodall attempted to take his life in the months before departing for Switzerland. Tragically this is not an isolated story and an increasing number of those suffering serious and incurable conditions are taking drastic and often violent measures to kill themselves rather than face the possibility of a bad death.

The 2016 Victorian Parliamentary Committee of Inquiry into End of Life Choices heard that around 50 Victorians a year take their lives after “experiencing an irreversible deterioration in physical health”. An emotional Coroner described cases of hangings, suffocation, gunshots, poisoning and other distressing and violent

deaths, including a 90 year old man with cancer who died from nail gun wounds to his head and chest. The trauma to the families left behind and to emergency services workers cannot be overstated.

We must not look away from these deaths. We must overcome our reluctance to speak frankly about death and dying. We must better understand the process of dying and prepare for what is ahead of us in terms of our medical care and the impact on our daily lives and on our carers and loved ones.

We need to talk openly with our families and doctors about our wishes and make fully informed decisions about our rights to accept or refuse medical treatment and record those decisions in advance care directives.

We must lobby for better palliative care services in the community and in aged care facilities. The medical profession needs to communicate better with patients about their end of life options and recognise that their natural inclination to prolong life does not always accord with the patient’s wishes or best interest.

The desire for a ‘good death’ is universal and I hope that Professor Goodall’s story and campaign for voluntary assisted dying laws for the terminally ill will prompt more open and honest discussions within families, the medical profession and the community about death and dying. Surely we can do better than having our elderly people killing themselves in lonely and violent circumstances because they fear the pain and suffering of a ‘natural death’.

Recognition of Professor Brian Owler

Professor Brian Owler, NSW neurosurgeon and former AMA President (2014-2016), was recognised in the Queen's Birthday Honours List on 11 June: "For significant service to medicine through the leadership and administration of professional medical organisations, and to education."



We would like to thank Professor Owler for his courage and advocacy. He played a critical role as the Chair of the Victorian Ministerial Advisory Panel, which was instrumental in the passage of the Victorian *Voluntary Assisted Dying Bill 2017*.

New Board member

We were delighted to welcome Debbie Ditchfield (pictured) to the Dying with Dignity NSW Board of Directors in April.



After volunteering at polling booths for the Voluntary Euthanasia Party in the 2015 State and 2016 Federal elections, Debbie decided she wanted to become more involved in our cause. Debbie brings much needed skills and energy to our organisation as we gear up to another campaign to legalise voluntary assisted dying in NSW in 2019.

Reports from related groups

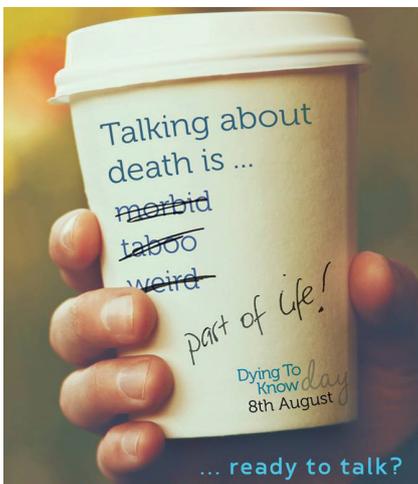
Mid North Coast group

Last year many of our local members requested a guest speaker to educate us about medicinal cannabis. Fortunately Paul and Sharlene Mavor from Perth agreed to attend our 15 May meeting as they were speaking at a conference in Sydney only a few days before. The media was very interested in the topic and we got extensive regional media coverage with radio interviews and newspaper stories in the days before the meeting. This attracted a crowd of about 80 people. *Prime7* and *WIN TV* camera crews and journalists also came and filed excellent reports, featuring interviews with members and guest speakers on their news bulletins that evening.



Paul and Sharlene Mavor were engrossing speakers, sharing the wealth of knowledge they have gained from doing global research. They have established Medicinal Cannabis Research Australia.

Dying to Know Day



8 August is Dying to Know Day (D2KDay). This annual celebration was first held on 8 August 2013. D2KDay is an opportunity to take a personal action, such as making your advance care plan or having a conversation about your end-of-life wishes.

Attend a D2KDay event to 'bring to life' community conversations about death, dying and voluntary assisted dying - you can find an event in your area via www.dyingtoknowday.org.

Or perhaps you might consider hosting your own event. Event packs, books, discussion cards, downloadable resources and more are available at www.dyingtoknowday.org/resources/.

Interestingly, Paul is a pharmacist and was initially a sceptic about the therapeutic effects of medicinal cannabis. To say that the audience was very engaged is an understatement. Lots of questions were asked and answered.

We have been asked to participate in a three person panel discussion as part of the Port Macquarie Hastings Library's 'Locals Talk' initiative, as a Dying to Know Day event. It will be held at the library on Saturday, 11 August at 10 am. Places are limited to 50 attendees. RSVP directly to the library on 6581 8755 or email portlib@mnclibrary.org.au.

We look forward to welcoming our DWD NSW President, Penny Hackett, as the guest speaker for our 28 August 2018 meeting. I urge you all to attend, as this is an opportunity for us to participate in setting the agenda for the campaign.

We are organising a panel discussion on 'Living with a terminal illness' for our November meeting.



Huge thanks to Suzanne, Robyn, Susan and Pam for volunteering on our information stall at the recent Seniors Expo. I have it on good authority that you were all very good at promoting our cause and we now have lots of new supporters. Paul Newman did a great job organising and setting-up our stall. Thank you Paul for all that you do for DWD.

I encourage any of you involved in a community group to nominate a speaker from our Mid North Coast DWD group to help build awareness.

Our meetings are held from 10 am till noon in the Rushcutter Room in Port Panthers Club, 1 Bay St, Port Macquarie. Thanks to Port Panthers for donating the meeting room and setting up/packing up all the seating and tea/coffee station. \$5 entry includes morning tea. Everyone is welcome. See you all at our 28 August meeting.

Annie Quadroy

Mid North Coast NSW Group Convenor
email: pmq@dwdnsw.org.au
Mob 0432 048 414

Central Coast group



Guest speaker and Life member of DWD NSW, Stuart Carter (pictured), gave a multi-media presentation on 'Advance Planning for Later Life' to our May meeting. His subject was both topical and extremely informative and many questions were asked in the Q&A session which followed.

The remaining two Friday meetings for 2018 are:

Friday 17 August: Richard Mills, former DWD NSW President (2012 to 2014), will speak about 'Looking back over years of campaigning to achieve legalised Voluntary Assisted Dying in NSW.'

Friday 23 November: Penny Hackett, current DWD NSW President, will explain the latest plans and tactics in 'Towards achieving Voluntary Assisted Dying in NSW in 2019'.

The rest of this year promises to be a very busy time for the Central Coast group and all of DWD NSW, as we build awareness and strengthen relationships with the key stakeholders in preparation for the next NSW bill.

Invitation to a special event: As part of this important preparation phase, we are very pleased that Senator Richard Di Natale, leader of the Australian Greens, has agreed to speak to us at a special meeting of members and guests on Tuesday 31 July at 2 pm in our usual venue. Everyone is invited to come along and hear from Senator Di Natale.

All our meetings are in Meeting Room No. 3, The Hive, Erina Fair (opposite the Erina Library desk). Everyone is most welcome.

If you are not on our Central Coast group email list and want to hear about our events please send your details to centralcoast@dwdnsw.org.au or phone me on 02 4322 4053.

Beverley Symons

Central Coast NSW Group Co-ordinator
Email: centralcoast@dwdnsw.org.au

Christians for VE Choice

On 30 May I was surprised and delighted to read 'Survey reveals Christians support assisted dying' as a headline in *CathNews.com*. Readers of DWD newsletters would already be aware of Christian support for this issue but it would be a 'revelation' to many of the folk receiving what is described as Australia's leading Catholic news service.

The *CathNews.com* article went on to quote from an article entitled 'How your religion changes your views on the right to die' published in *The Canberra Times* on 29 May that "Many Christians are at odds with religious leaders on euthanasia, with some denominations more supportive of voluntary assisted dying than others". It also reproduced some of the reported survey results, including "Sixty-eight per cent of Uniting Church members and Catholics agreed euthanasia was an acceptable solution for terminal or extreme physical illnesses, as did 63 per cent of Anglicans, 44 per cent of other Christians and 59 per cent of other religious respondents."

It is significant and encouraging that one of the report's authors, Professor Anthony Hogan – who is an adjunct research professor with The Australian Centre for Christianity and Culture – said the survey findings supported the idea that some formal theological positions do not reflect the "views of the pews".

Both the *CathNews.com* and *The Canberra Times* articles also refer to Canberra's Catholic Archbishop Christopher Prowse and his evidence to the ACT Inquiry into End-of-life Choices as reported in *The Age* on 18 May. Archbishop Prowse unsurprisingly asserted the official church dogma opposing voluntary assisted dying choice by



Archbishop Christopher Prowse greets Pope Francis

saying to the committee that it was "inhumane and dehumanising" and attempting to generate unreasonable fear, uncertainty and doubt (FUD) that "the vulnerable would be at risk" etc!

The comments from Archbishop Prowse motivated me to send him a detailed letter rebutting his claims and deploring his lack of compassion for those dying with extreme suffering. My letter concluded with the following observations: "... Yet you and the hierarchy of the Catholic Church insist that your beliefs on assisted dying choice should override the rights of other Australians to choose. Not between life and death, because by definition a terminal patient is going to die – but between two ways of dying – one quick and painfree.

"Evidence recently given by countless victims of Catholic paedophile priests clearly show the abyss and total lack of understanding by the Catholic Church for the suffering endured by those victims. Many of these victims went on to take their own lives in dreadful circumstances - in a cruel irony compared with the Church position on voluntary assisted dying.

"I certainly do not write in the hope of changing your mind on this issue. By all means feel free to endure whatever suffering comes your way in your end of life, but I do pray and urge you not to use your position to force me and every other Australian to do the same."

Readers with internet access can read the full Prowse article and my complete letter on our website: www.christiansforve.org.au/news.

Membership of our Australia-wide group is free, and open to all who support our compassionate Christian approach to voluntary assisted dying.

Join us via our website christiansforve.org.au or simply let me know your name, address and religious denomination (if you have one) - by email to ian.wood@christiansforve.org.au or by post to Villa 1/4 Wills Place, Mittagong NSW 2575.

Kind regards,

Ian Wood

National Co-ordinator, Christians Supporting Choice for Voluntary Euthanasia

Voluntary Euthanasia Party NSW

As you may be aware, the Voluntary Euthanasia Party (VEP) was established in 2013 to provide an avenue for individuals who support voluntary assisted dying (VAD) laws to express their wishes at the ballot box. VEP is a single issue political party with the same goal as Dying with Dignity NSW.

Many members and supporters of DWD NSW also support the VEP.

VEP has run candidates in three elections over the past five years, twice in Federal elections and once in the 2015 NSW state election.

Following the disappointing defeat of the NSW *Voluntary Assisted Dying Bill* last November, VEP NSW has been making plans for the next NSW state election, which will take place on 23 March 2019. Participating in the political process is a powerful means of affecting change.

Whilst the VEP ultimately hopes to get a member of the party elected to the NSW Upper House, the campaigning in the lead-up to the March 2019 election is of value in itself as it helps draw public attention to the need for laws to permit VAD. This benefits the cause which we are all so passionate about. Importantly, it will also help to support our efforts to persuade NSW MPs to vote for VAD laws when another bill is put before Parliament, hopefully in the months following the election.



Shayne Higson with Stan Malicki and others demonstrating outside the NSW Parliament House on 16 November 2017

VEP(NSW) have recently announced their first and second candidates for the NSW Upper House. They are Shayne Higson and Paul Gabrielides, both of whom will be very familiar to DWD NSW members and supporters. Shayne Higson has been a high profile campaigner for VAD laws since witnessing

the terrible death of her mother from brain cancer in 2012. She has been associated with the VEP since it was formed in 2013 and has contested three elections over the past five years, twice as a Senate candidate and once as the VEP's lead candidate for the NSW Upper House. Between elections, Shayne has continued to work on the campaign to legalise VAD in her roles with Dying With Dignity NSW (of which she is presently Vice President) and Go Gentle Australia.

Paul Gabrielides (pictured) was the husband of Annie who was the 'face' of DWD NSW's 2017 campaign for the NSW *Voluntary Assisted Dying Bill*. Annie started a petition on Change.org which received over 115,000



signatures. She lost her battle with Motor Neurone Disease in January 2018. Sadly, despite the support of a compassionate team of palliative care nurses and doctors, Annie did not have a peaceful death.

In announcing his intention to stand as a VEP candidate, Paul explained to the supporters of Annie's Change.org petition: "I made Anne two promises. The first one, that she would not suffer a bad death, I was not able to keep, and this will burn a hole in my heart for the rest of my time. I am not the kind of man who breaks promises, so having broken the first promise, I have no intention of breaking the second one. I promised Anne that I will, like her, leave nothing in reserve in my fight to ensure this law is changed, and the people of our state and our nation achieve SELF-DETERMINATION."

Paul and Shayne know that 85% of Australians believe that someone dying of a terminal or incurable illness should have the right to choose a peaceful and dignified death with compassionate, medical assistance. They will work as hard as they can to promote the cause and, if possible, win seats in the NSW Parliament to make sure that the next VAD bill in NSW is passed into law. If you would like more information about the VEP and Shayne and Paul's campaign, visit:

www.vep.org.au/2019_nsw_election

Become a member of Dying with Dignity NSW

Complete the form below or sign up at dwdnsw.org.au/membership

Existing members should have received their renewal notice by post or email

Dying with Dignity
New South Wales



**Membership
Form**

Page 1

Full name: Year of birth:

Postal Address:

Residential Address (to determine your electorate):

Are you happy to receive our newsletters via Email rather than Post? YES / NO (please circle one)

Email Address (if you use email fairly regularly):

Mobile: Landline:

Occupation (optional):

Please tick the box if you are a medical doctor, nurse or other health professional.
If you have ticked the box please provide brief details below:

.....

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Plus DONATION (optional - please write the amount of your donation) \$ _____

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Total Amount to be charged to your card (*from page 1*): \$ _____

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Or scan the completed form and email the copy to us at dwd@dwdnsw.org.au

If you support our campaign for law reform but are unable to join at the present time, you are welcome to join our free email list for supporters. Simply send us an email to dwd@dwdnsw.org.au containing your name, residential suburb and email address.

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Anne Mauchle's path to a dignified death

By Anne's husband, Andre Mauchle

Anne closed her eyes slowly. I thought I saw the faintest trace of a smile. Holding her hand I knew that she was slipping away to where she wanted to be. She could not have wished for a more peaceful and dignified death.

Anne's journey from an intelligent, vibrant woman to ending her life in Switzerland started a long time ago. For most of her life, Anne worked as a Baby Health Nurse and a Consultant mentoring other nurses. She was highly regarded for her knowledge and warmth. In 1988, at age 36, Anne experienced some small cognitive changes. It was only much later that this was recognised as the likely beginning of her dementia.

In 1997 further symptoms of her illness emerged. For two days Anne found herself totally confused. She didn't know where she had parked her car, she got lost in the street, couldn't distinguish coins, had difficulty with her short term memory and struggled with simple tasks. At the same time she started to develop a tremor in her hands.

Anne's GP referred her to a neurologist, who carried out a number of tests. They indicated that Anne had a non-specific abnormality in her left temporal lobe. During the next ten years Anne continued working in various capacities within her job. Over time she noticed small but continuous changes in her cognitive ability.

Anne started seeing a psychiatrist, a neuropsychiatrist, a neuropsychologist, a neurologist and had multiple MRI and P.E.T. scans. Eventually she was diagnosed as having an atypical frontal lobe dementia. This is a progressive neurodegenerative disease that slowly worsens over time.

The years following her retirement in 2010 were punctuated by a slow process of losing more and more ability to plan and organise, a decline in visual and physical aspects, including imbalance and loss of fine motor skills. These changes were not noticeable by people who saw her infrequently, but they were noticeable to me.

Although Anne made the decision to end her life in 2017, we had been talking about this option for the previous ten years. We had often spoken about her symptoms, her experiences, 'what ifs' and what the future would hold. She knew her illness was progressive and that she would probably end up in a nursing home. She knew what that would entail and did not want it. This realisation was very upsetting and stressful for both of us.



Anne had dual citizenship of Australia and Switzerland. During a visit to Switzerland in 2010 Anne visited EXIT Deutsche Schweiz (DS) and became a member.

EXIT (DS) provides assisted dying to eligible Swiss citizens or permanent residents of Switzerland. To be eligible a person must have an illness or condition which has a hopeless prognosis and unbearable symptoms. Dementia is an eligible condition, provided the patient retains the capacity to give informed consent. Anne knew that she had to make a decision while she was still cognitively aware and able to give informed consent to any 'treatment'.

For Anne, having a death assisted by EXIT (DS) was the obvious choice. (Dignitas provides similar end-of-life services to eligible residents and non-residents, but for a higher fee.) Anne was fully at peace with her decision to make this choice. However, she still experienced some psychological distress associated with her decision, because of her knowledge of the anguish and sadness that her death would cause to our family and friends.

In January 2017 Anne experienced what she described as an electrical storm in her brain, which lasted about 10 seconds. This was the moment when it became clear to her that it was time to organise her last trip to Switzerland.

continued from page 11

Within two months of the dreadful January seizure we were in Switzerland. Some of our friends and family had difficulty coping with our departure, however the vast majority considered her courageous and supported her fully.

Ten days later, on 8 April 2017, Anne entered the dying room of EXIT (DS) accompanied by myself and our close friend. The last moments of her life were truly dignified and peaceful. Anne, having made her decision a long time ago, was at peace and ready for the final step. I was lying on the bed next to her, holding her in my arms with her chosen music playing, when her breath finally stopped.

Editor's notes:

There have been many bills seeking to legalise voluntary assisted dying presented to Australian State Parliaments. They have all excluded people suffering from all forms of dementia. While many in the community want this option, such a bill is unlikely to be passed by our politicians.

Anne Mauchle was assisted by EXIT (Deutsche Schweiz). This organisation is not related to EXIT International, founded by Philip Nitschke.



Donate in
memory of
a loved one

Donations made in honour of Anne

After Anne's death, Andre and their friends and family held a 'Celebration of Life' event in Australia in memory of Anne. Andre asked that people donate to Dying with Dignity NSW in lieu of bringing flowers. The generosity of Anne's family and friends helped us to raise a large donation in Anne's honour. Our board members thank Andre and Anne for their long-standing support for our campaign to provide end-of-life choice to the people of NSW.

Following is more information about the Swiss law and what is available to foreigners.

Assisted dying in Switzerland

Since 1942 Switzerland has allowed voluntary assisted dying (VAD) provided the motives of the person assisting are not selfish. Switzerland is the only country in the world that allows non-citizens to receive VAD provided they meet strict criteria:

- 18 years or over
- capable of sound judgement; able to consent to the procedure
- able to administer the lethal substance to themselves
- does not have a mental illness

While we do not know how many Australians travel to Switzerland to end their lives, anecdotally we believe a small but increasing number are pursuing this option. There are three main Swiss organisations offering an assisted death:

Dignitas is the most prominent Swiss organisation providing VAD to foreigners. It was founded in May 1998 with the aim of allowing non-Swiss individuals access to the proven Swiss model of freedom of choice, self-determination and personal responsibility at life's end. Since 2012 Dignitas has provided VAD to just over 200 people per year.

Lifecircle started in 2011 and offers VAD to foreigners and people living in Switzerland.

EXIT (Deutsche Schweiz) started in 1982 and provides VAD to Swiss citizens only. It is not related to EXIT International founded by Philip Nitschke.

Just after Professor Goodall's death in Switzerland (see pages 3 to 5), columnist Nikki Gemmel wrote in *The Weekend Australian* (12 May) about her friend Helena who chose VAD at Dignitas in 2017.

Gemmel wrote: "I think of Helena's face glowing with radiant certainty as she said a happy goodbye before boarding the plane to Switzerland... She passed away in her Dignitas room in exactly the manner she'd wished for, with everyone holding hands, in a space brimming with love. She was ready. The chronic pain had exhausted her almost to the point of incapacity and she no longer wanted to live like that. She had a good, strong and, dare I say it, joyful death."

Gemmel's description makes having an assisted death in Switzerland sound like a simple option for foreigners who wish to die. This is not the case, as it is a complex and expensive process which involves many challenges including:

- The approval process is very lengthy, with a Swiss physician having to review the formal request to ensure that assisting the applicant's death would meet with Swiss guidelines. The request must include a letter explaining the person's wish to die and full medical reports showing the diagnosis and treatments that have already been tried.
- The assessment requires two personal discussions between the physician and the person making the request. Consequently, the person must plan to stay in Switzerland for 3 or 4 days to attend these meetings before they die.
- The cost of about \$15,000 plus airfare and accommodation is prohibitive for many people.
- The long journey from Australia could be very difficult, especially if the person is at a stage where they are in great pain and distress.
- People often choose to die earlier than necessary due to fear that they will not be able to make the journey when they are very sick.
- Anyone who accompanies the person overseas to have VAD could be charged with assisting a suicide and be liable to imprisonment in Australia upon their return.



Terry Pratchett says goodbye to Peter Smedley from the UK just before his assisted death at Dignitas in 2010 - screenshot from the documentary 'Choosing to Die' (2011).

A statement from Dignitas in August 2017 included the warning that "Preparing and carrying out accompanied suicide is very labour-intensive and complex, especially with individuals from abroad. The costs associated with it cannot always be fully borne by the members themselves. The Swiss legal system imposes strict rules about allowing people from abroad to have access to a voluntary assisted death with Dignitas, investigating every death to ensure safety and transparency." (See the DWD NSW website for the full statement by Dignitas.)

Interstate News

Western Australia (WA)

The WA Labor Premier, Mark McGowan, elected in March 2017, supports the passage of voluntary assisted dying (VAD) legislation for WA. Last August the WA Parliament launched an Inquiry Into End of Life Choices similar to the one held in Victoria. The Inquiry received over 650 written submissions and has held over 80 public hearings, demonstrating a high level of interest within the community. Many witnesses shared very personal and profound experiences and, although the Inquiry has received evidence from both sides of the debate, there certainly appears to be growing support for VAD.

As with the Victorian Inquiry, the WA Inquiry is bringing together a valuable collection of information from doctors, nurses and others with extensive experience of end-of-life health care in WA, including members of Doctors for Assisted Dying Choice. For example, in February WA Anaesthetist Dr Peter Beahan told the Committee that "about 20 per cent of those who receive terminal sedation may experience some suffering" whereas VAD "is quick, painless and certain".

Dr Beahan explained that "Patients do not fear death; they fear the process of dying, and with good reason." At the same hearing, WA public health physician Dr Richard Lugg stated that "In our view, and we are doctors after all, there will be advantages in having the area under the control of a health administration rather than a criminal justice administration."

Evidence provided to the Inquiry by State Coroner Ros Fogliani revealed that one person suffering a terminal or debilitating illness takes their own life every nine days in WA. These figures prompted the head of the WA Police Union, George Tilbury, to call for VAD to be legalised so that "there would be less horrific suicides, and first responders would be spared having to see as many graphic scenes, most of which stay with them forever".

All the written submissions and transcripts of all the public hearings are available on the Parliament website - www.parliament.wa.gov.au. From now until August, the focus of the Committee will be finalising their report to Parliament.

Australian Capital Territory and Northern Territory

On 30 November the Australian Capital Territory (ACT) Parliament established a Select Committee on End-of-life Choices in the ACT. Advocates for and against VAD have inundated the Inquiry with over 500 written submissions, some sharing heart-wrenching stories of watching suffering family members. One woman, who along with her 80-year-old husband was suffering from cancer, said she wanted the chance to “jump off the cliff while I’ve still got the health to climb it”.



The Committee began holding public hearings in May and is due to report to the ACT Legislative Assembly by late November 2018. The outcome of the ACT Inquiry is less straightforward than the other state Inquiries because the 1997 Federal law prevents Australian territories from making their own laws on VAD. It is hoped that the final report by the ACT Committee will convince the Federal Parliament to restore the rights of territories with regards to VAD.

Meanwhile in the Northern Territory, the Chief Minister, Michael Gunner, responded to the passage of the Victorian law by writing to Prime Minister Turnbull to demand the return of the territories’ right to self-government in respect of VAD laws.

Other Australian states

Victoria: On 29 November 2017, less than two weeks after our voluntary assisted dying (VAD) bill failed to pass in the NSW Upper House by just one vote, the Victorian Parliament made history by becoming the first Australian state to approve the introduction of a voluntary assisted dying scheme. The legislation is now going through an 18 month implementation period before it comes into effect in June 2019.

Tasmania: Supporters of VAD in Tasmania are very pleased with the results of their state election held in March. According to the President of DWD Tasmania, Margaret Sing, there is now in principle support for VAD by the majority in the House of Assembly and strong support in the Upper House. DWD Tasmania has started working with MPs with the aim of getting a bill presented to Parliament this year, with debate early in 2019.

Most of the supportive Tasmanian MPs have indicated they are likely to vote for a VAD bill similar to the one debated in Tasmania in 2017, which is closest to the Canadian approach. This provides a ‘last resort’ option for competent adults who have intolerable suffering due to their advanced, serious, incurable and irreversible illness with no chance of recovery, AND when both the person and their doctor agree there are no other options to improve the person’s condition or relieve their suffering.

South Australia: Much like the Tasmania election, the South Australian election in March has introduced many new MPs in both houses of Parliament, bringing with them renewed prospects. One third of the current House of Assembly MPs were not around for the 2016 debate on *The Death with Dignity Bill*, which was defeated by only one vote. *The Voluntary Euthanasia Bill*, introduced to the Legislative Council in 2010, was the last time that House has seen a VAD bill. That bill was narrowly defeated in a chamber that included only 13 of the current 22 members.

Members of the SA Voluntary Euthanasia Society (SAVES) are continuing to meet with MPs who will determine whether it is best to proceed with the introduction of a new bill into the Upper or Lower House or seek referral to a Parliamentary Inquiry. South Australia has had a number of Inquiries into end-of-life choices over the last thirty years, but the Hon Rob Lucas is the only sitting MP who was in Parliament at the time of the last Inquiry (1993-1995). Fresh eyes brings new hope for success.

Queensland: Despite the passing of a motion to legalise VAD by the Queensland Labor Party at their State Conference in July 2017, Labor Premier Annastacia Palaszczuk says she is watching the Victorian situation closely, but is also waiting on the Law Reform Commission’s report into abortion, which is the major reform priority for Labor before the next election in 2020. Despite the Premier’s

reluctance to prioritise VAD, the Chairman of the Clem Jones Trust, David Muir, is advocating strongly for VAD in Queensland with the backing of funds from the Clem Jones Estate. Muir has told the media “As a first step, I have written to all 93 state members encouraging them to open the conversation in their electorates so they know their constituents’ thoughts. This is not a political issue. It is an issue of compassion and of conscience”.

Overseas News

See page 16 for news from Hawaii and California.

United Kingdom

Guernsey: Guernsey is a self-governing British Crown dependency in the English Channel. Guernsey’s Chief Minister proposed a private member’s bill to legalise VAD. It was defeated on 18 May in the Guernsey Parliament after a three day debate. If it had passed, Guernsey would have become the first place in the British Isles to offer VAD for people with terminal illness. The bill was based on the Oregon model. It was opposed by Christian leaders, the Guernsey Disabilities Alliance and the British Medical Association.

Noel Conway: Since March 2017 Noel Conway, who has terminal Motor Neurone Disease and is now aged 68, has been fighting for his right to an assisted death (VAD) through the British courts.

Whilst Conway’s application was rejected by the High Court, he was granted leave to appeal. His case was heard in the Court of Appeal in early May. Conway’s lawyer explained that the appellate court had to decide whether the ban on VAD is justifiable for the specific cohort of people that Noel Conway represents - those who are terminally ill with less than six months to live. The decision is expected to be released soon. If Conway is successful it would be a very important precedent for the UK.



New Zealand (NZ)

David Seymour’s *End of Life Choice Bill* passed the First Reading stage on 13 December 2017 with 76 votes in favour and 44 against, moving it on to the Committee stage. Seymour’s bill is a bit broader than the 2017 NSW bill, including those who are not terminal but are “suffering from a grievous and irremediable medical condition, in an advanced state of irreversible decline in capability and experiencing unbearable suffering that cannot be relieved in a manner they consider tolerable.”

In a public meeting on 29 May Seymour explained: “I entered the *End of Life Choice Bill* to Parliament because New Zealanders overwhelmingly want choice... Opponents misunderstand my bill by painting the elderly as victims. Their misplaced compassion hurts people and denies them choice... It’s a decision that can only be made by the person in question, and there are safeguards in place to ensure they make this decision freely”.

The NZ Parliamentary Committee has received an unprecedented 35,000 submissions and has agreed to meet face-to-face with anyone who wishes to put their views in person. The result is that the Committee’s formal report is now not expected until March 2019, pushing back the likely date for the bill to come back before the NZ Parliament.

Portugal

After recently legalising same sex marriage and abortion, Portugal voted on a voluntary assisted dying (VAD) bill on 4 June. A 2016 petition in support of a VAD bill with more than 8,000 signatures pushed the issue onto the political agenda. This was more than double the amount needed to force a parliamentary debate. The bill proposed access to VAD for patients suffering profoundly from a serious, incurable illness with no expected improvement in sight, in a terminal state, or suffering from a seriously disabling condition.

The Portuguese Doctors Association opposed the bill and prior to the debate the Portuguese Episcopal Conference distributed 1.5 million pamphlets arguing against VAD. Nevertheless, the vote was surprisingly close, with 110 in favour, 115 against and 4 abstaining. This result was encouraging, given that 81% of the population of Portugal is Catholic (2011 Census).

"I think those who have a terminal illness and are in great pain should have the right to choose to end their lives and those that help them should be free from prosecution."

prosecution."

- Stephen Hawking



Professor Stephen Hawking
1942 to 2018
Rest In Peace

Farewell Professor Stephen Hawking, perhaps the most remarkable intellect of our time, who suffered Motor Neurone Disease - one of life's cruelest afflictions.

Who better than you to understand the value of life and the meaning of death?

Thank you for the public support you gave to voluntary assisted dying.

Success in Hawaii

Great news from America - Hawaii has just become the eighth jurisdiction in the United States to legalise voluntary assisted dying. Their law, known as the *Our Care, Our Choice Act*, was passed by Hawaii's Lower House in early March and on the 29 March the Senate passed it with a resounding 23 votes to 2.



The Hawaiian *Our Care, Our Choice Act* will take effect on 1 Jan 2019. It is modelled on Oregon's *Death With Dignity Act (1997)*, allowing an adult resident of Hawaii who is mentally competent, terminally ill and within six months of death, to obtain a prescription for a substance which that person can self-administer to end their life at the time of their choosing.

Californian set-back

Not such good news from California. In May the County Court Judge Daniel Ottolia overturned their *End of Life Options Act*, modelled on the Oregon law, which was effective from June 2016. Judge Ottolia granted the motion to invalidate the law because it was passed during a special session of Parliament limited to health care issues. The case was brought by a group of Right-to-Life lawyers and doctors who argued that assisted dying is not a healthcare issue.

Judge Ottolia also scheduled a hearing for 29 June to consider a separate motion by California Attorney General Xavier Becerra to vacate the judgment. Technically, the *End of Life Options Act* remains in place but the uncertainty around its future is leaving patients unclear about how to proceed.

For an estimated 200 patients who had already started the process of hastening their deaths, the decision has sparked confusion and fear. Kat West of Compassion & Choices has reported that doctors have stopped writing prescriptions for the lethal medication and pharmacists have stopped filling those already written.

"We are besieged with calls from anxious, confused, terminally ill Californians, doctors and health care providers about the status of the law," said Kevin Díaz, also from Compassion & Choices.

This issue will be fought through the many layers of the US justice system. We join the overwhelming majority of Californians in hoping that the lower court ruling will be reversed and the law reinstated.

Dying with Dignity NSW is an advocacy organisation pursuing a change in the law that will enhance choice at the end of life. We seek legislation that enables competent adults experiencing unrelievable suffering from a terminal or incurable illness to receive medical assistance to end their life peacefully, at a time of their choosing.

JOIN US NOW.

website www.dwdnsw.org.au

DONATE NOW.