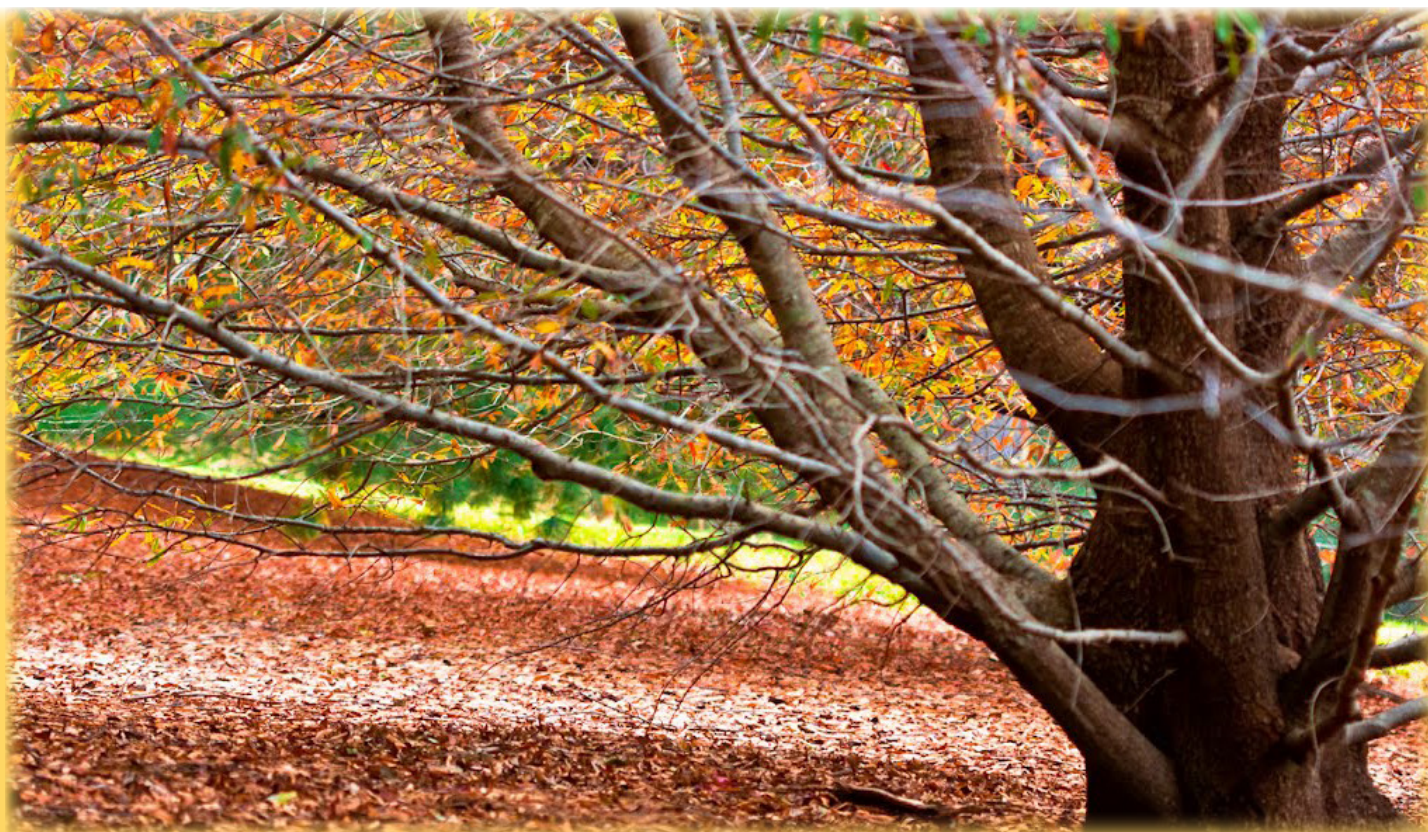




AUTUMN 2017

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President's message



This year we are closer than ever before to seeing the legalisation of voluntary assisted dying (VAD), with bills being tabled in Victoria, NSW, Tasmania and WA. Our biggest hope is Victoria, where a lot of ground work has already been done (see page 3).

We are also cautiously optimistic about the chances of the *NSW Voluntary Assisted Dying Bill* passing the Upper House later this year. During March, four members of the Dying with Dignity NSW board met with members of the NSW Parliamentary Cross Party Working Group on Assisted Dying to discuss progress on the bill and plan strategies. We left the meeting with lots of useful information and the view that the bill has a reasonable chance of success, at least in the Upper House.

The working group has been at pains to consult widely to ensure that every possible obstacle to its passage is considered. To this end there have been numerous revisions, and the working group is still awaiting further submissions from stakeholders before the final exposure draft is released for public comment, most likely by the end of April, with debate likely to occur around August this year.

A lesson learned from the recent South Australian experience is that the final bill presented to Parliament must be extremely 'tight', and we hope that with the rigorous process in NSW we can avoid last-minute rewrites in the lead-up to the debate. Reflecting on the contents of the NSW bill, the DWD NSW board believes that the current provisions do not go far enough. We believe that VAD should be available not just for individuals with terminal illness, but for those facing unrelievable and unbearable suffering. Nevertheless, we are also pragmatists and recognise that '75% of something is better than 100% of nothing'. Given the history of repeated failures of VAD bills over the last three decades, the passage of this bill would be a huge advance, and deserves our support.

We are currently working closely with the working group and planning a campaign to ensure maximum impact prior to the debate. We will also write to our members in upcoming months to ask for your help in communicating with MPs. The timing of this contact depends upon the date that the NSW exposure draft is released.

One of the most effective tools for influencing public opinion are the personal stories of individuals who are affected by our current laws. We are therefore extremely grateful to DWD member Annie G, who was diagnosed with motor neurone disease in 2016. During January, Shayne Higson and I accompanied filmmaker, Luke Cornish, to Annie's home, where Luke recorded interviews with Annie and her family members. The result is an enormously powerful nine minute video that provides a most compelling case for a change in the law. The video will be released for maximum effect in the lead-up to the NSW campaign, and we hope that those of you who use social media will be able to help us share it. (A shorter version will also be available for sharing).

Finally, our AGM is on 27 May (see back cover for details). I will provide an update on the latest campaign news, and we will also present an audited financial report. I am delighted that Professor Colleen Cartwright has agreed to be our keynote speaker. Colleen is a legal expert in matters related to dying, including advance care directives, individual rights at end of life, and potential changes in the law. She is a dynamic presenter and will no doubt provide a very interesting speech. The AGM is also a great opportunity to find out more about our organisation, meet with our board and other DWD members, and participate in the democratic process. I hope to see you there!

As always, thank you for your support.

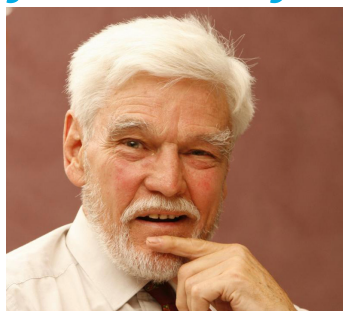
Sarah Edelman

President, DWD NSW



2016 Annual General Meeting

2017 Australian humanist of the year - Dr Syme



Congratulations to Dr Rodney Syme, pictured, for his recent recognition as *Australian Humanist of the Year for 2017* by the Council of Australian Humanist Societies. The award was made for his advocacy and support for voluntary assisted dying (VAD). Dr Syme will be presented with the award at The Australian Humanist of the Year Gala Dinner on Saturday 8 April in Melbourne, as part of the annual Australian Humanist Convention.

Scott Sharrad, President of the *Council of Australian Humanists Societies*, said “*Dr Syme’s efforts to bring true choice to people facing incurable suffering and terminal illness away from the influence of religious dogma are important for Humanists to recognise.*”

For information about Dr Syme’s new book, *Time To Die*, see page 15.

Victoria

The Victorian Government is moving forward with plans to introduce a VAD bill in the second half of the year. Much of the groundwork was laid by *The Victorian Parliamentary Inquiry into End Of Life Choices Final Report*. The Victorian bill will have the advantage of being initiated by the government and having the support of the Premier, Daniel Andrews, as well as many government ministers. This is in contrast to all previous Australian VAD bills in the various states, that have all been private member’s bills.

Earlier this year, the Victorian Health Minister, Jill Hennessy, introduced a further layer of consultation when she appointed an expert panel to advise on technical aspects of the legislation. The panel, led by former AMA President, Professor Brian Owler, is consulting with stakeholders (including doctors, nurses and palliative care specialists), on key areas of the legislation, including eligibility and safeguards. Comments close on April 10.

The Victorian Health Minister has made it clear that the legislation will have a narrow scope, similar to legislation that has operated successfully in Oregon USA for nearly two decades.

We need your help

We are planning a vigorous campaign to ensure that the *NSW Voluntary Assisted Dying Bill 2017* is passed. We need your help in our lobbying efforts, especially once the NSW bill is released as an Exposure Draft. We urge you to contact members of the NSW Upper House and your local State MP to tell them your personal story and why you are in favour of changing the law. (If you think you have a powerful personal story that you want to share with us, you can phone Shane Higson on 0428 326 358.)

The most effective way to influence politicians is face-to-face; by making an appointment and visiting them at their office. Going with one or two local people can make it easier, if you are not confident to go alone. If you are not able to do this, posting a letter to politicians, or talking to them over the phone, can also be an effective way of communicating your view.

All their contact details are found on the Parliament of NSW website: www.parliament.nsw.gov.au/members.

It also helps DWD NSW to advocate on behalf of a large membership base, so if you have not yet become a financial member of DWD NSW, you might consider doing so in 2017.

You can join via our website www.dwdnsw.org.au or phone us on 02 9212 4782 to have a membership form posted out to you.



Tribunal ruling supports Dr Syme against Medical Board

In 2016, ABC's *Australian Story* aired a program about Bernard Erica, who was suffering with terminal cancer of the tongue and lung. The program included an interview with Dr Rodney Syme, who openly offered to provide Mr Erica with the lethal drug, Nembutal.

The Australian Medical Board subsequently ruled that Dr Syme posed a serious risk to persons generally, and to Mr Erica in particular. The Board threatened Dr Syme with deregistration if he proceeded with his intention of *"engaging in the provision of any form of medical care, or any professional conduct in his capacity as a medical practitioner, that has the primary purpose of ending a person's life"*.

In 2016, Dr Syme appealed the Board's decision at The Victorian Civil and Administrative Tribunal (VCAT). In December VCAT handed down the decision that it accepted that Dr Syme's primary purpose in providing Nembutal was for palliative care, in the form of psychological relief to the dying patient, who may or may not decide to eventually take the drug. VCAT concluded that the provision of Nembutal to provide psychological relief could have the "double effect" of ending a patient's life', but that Dr Syme's purpose was not primarily to assist patients to die, however likely this might be.

The principle of "double effect" is well established in Australian law to give legal protection for doctors who use aggressive treatments to relieve the suffering of terminally ill patients, knowing that they may simultaneously cause or hasten death. The doctrine makes intention in the mind of the doctor a crucial factor in judging their action. Unfortunately this judgement is very subjective and currently leaves patients and doctors feeling vulnerable under the law.

VCAT's statement in Dr Syme's hearing is significant: *'It should be emphasised that the Tribunal is not concerned in this application with the illegality or otherwise of Dr Syme's conduct in obtaining the drug Nembutal or giving it to a patient. However, the Tribunal notes that Dr Syme's conduct in this respect could hardly have been more public and there is no evidence before the Tribunal that he has ever been investigated, charged or prosecuted for any related breach of the law.'*



Dr Rodney Syme and Mr Bernard Erica
(*Australian Story*: Jackie Cohen)

An excellent article in *The Conversation* by Professor Simon Chapman, Emeritus Professor in Public Health at University of Sydney, describes these events in detail and sums up the consequences of the VCAT ruling:

'VCAT's decision is of immense importance. Its decisions can be cited in evidence, and so may be used as legal precedents. VCAT accepted Syme's defence (that his supply of Nembutal to dying patients was a legitimate and important part of palliative care). This means that other doctors around Australia may seek and perhaps succeed in using a similar argument should they be questioned by disciplinary authorities like the Medical Board or the police. Those with terminal illnesses wanting the right to end their own life using Nembutal have a lot for which to thank Rodney Syme.'

Go Gentle Australia

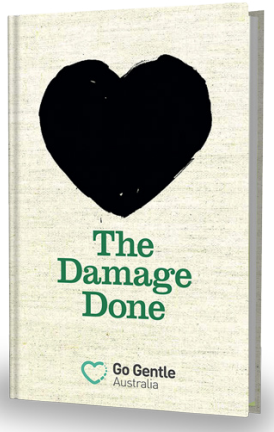


Andrew Denton in Sky News Panel on VAD 24 September 2016

Andrew Denton's organisation Go Gentle Australia (GGA), formed in 2016, is a not-for-profit company, working to support the right of those suffering from untreatable or terminal illness to have the option of an assisted death.

During 2016 GGA focused its efforts on the South Australian (SA) campaign, supporting The South Australian Voluntary Euthanasia Society and the MPs who sponsored two assisted dying bills. GGA coordinated a very strong media campaign, so that the issue dominated Adelaide media at key points of the campaign.

A compelling selection of personal stories of those who suffered needlessly at the end of life was published in GGA's book, *The Damage Done*, which was given to all SA politicians and key stakeholders. It was a powerful resource, and together with the



social media campaign based around 35 year old Port Pirie woman, Kylie Monaghan, who was in the final stages of cancer, reminded politicians of the human cost of the current laws. The campaign spread nationally, with coverage by *60 Minutes* and *The Australian* newspaper, as well as news and magazine

websites such as *Mamamia*. This ensured that South Australian MPs were aware that the eyes of the nation were upon them.

Following the defeat of the SA *Death with Dignity Bill 2016* (the bill was tied with the speaker casting his deciding vote against it), Go Gentle Australia's advocacy has now moved to Victoria. Over the past few months, Andrew Denton and GGA Campaign Manager, David Hardaker, have been laying the groundwork in Victoria, meeting with key stakeholders and building important alliances.

Although Victoria will be the primary focus for GGA this year, DWD NSW and the campaign for law reform in NSW (and other states) will benefit from a close relationship with Andrew Denton and his organisation. There will be collaboration in regard to campaign strategy, media exposure, stakeholder engagement, etc.

For more information about GGA, or to download the ebook or buy the printed copy of *The Damage Done*, go to www.gogentleaustralia.org.au.

Shayne Higson

Spokesperson for Go Gentle Australia
DWD NSW Board Member

Doctors for Assisted Dying Choice



Dr David Leaf

Doctors for Assisted Dying Choice represents the views of medical practitioners around Australia who support Voluntary Assisted Dying.

Membership is drawn from various specialties, and includes doctors with research, academic and medical administration experience.

The organisation, previously known as Doctors for Voluntary Euthanasia, aims to contribute expert medical opinion to politicians, medical colleagues, community groups and the media. Our opinions are evidence-based and secular.

We regard assisted dying as a medical conversation that should be held between a doctor and their patient, as well as their families. We believe that it should be part of a range of options available to a person who is facing unrelievable suffering.

State committees have been set up in NSW, Tasmania and Victoria. These committees form a national executive group that meets regularly to discuss strategies and draw from the collective knowledge and experience of the group.

If you are a medical doctor practicing anywhere in Australia, or even retired, you are warmly invited to join the group via the website drs4assisteddyingchoice.org.

Dr David Leaf

Sydney GP and Emergency Doctor
NSW Convenor Doctors for Assisted Dying Choice
Voluntary Euthanasia Party NSW Committee Member
DWD NSW Board member (2009 to 2013)

Western Australia

The recent defeat of Colin Barnett's government has improved the chances of a voluntary assisted dying (VAD) bill succeeding in Western Australia (WA). Mark McGowan, the newly elected WA Premier, and the new Health Minister, Roger Cook, have both openly supported introducing VAD legalisation.

During 2016, a WA Cross Party Parliamentary Committee began drafting a new VAD bill called *The Freedom of Choice At The End Of Life Bill*. Key figures include Labor MLC Alannah MacTiernan, Liberal MLA Tony Simpson and Greens MLC Robin Chapple. They are likely to play a major role in the putting together of new legislation.

Perth GP, Dr Alida Lancee (whose personal testimony appears in GGA's book *The Damage Done*), ran against Colin Barnett at the election, in order to highlight the lack of government support for this popular issue. In the lead-up to the election Dr Lancee, in collaboration with DWD WA, sought the views of candidates on the proposed bill and publicised them on her how-to-vote card.

advertisement

Freedom of Choice at the End of Life

Dr Alida Lancee

Take Care how you Vote!

Your Freedom of Choice may be REJECTED

A Bill will be introduced this year by members of all three major parties. This Bill will allow a terminally ill adult to request medical help to die gently and quickly rather than slowly in pain and anguish. There will be strict safeguards in place to ensure it applies only for whom it is intended. This Bill will benefit every one of us, if only by knowing the choice is there.

83% of us want this Bill (2014 WA Speaks Survey 10,000 responses)

A vote for these candidates may mean your Freedom of Choice is:

Electoral District	WA Labor	Liberal	Greens
Bicton	Lisa O'MALLEY ✓	Matt TAYLOR ✗	APPROVED
Kalamunda	Matthew HUGHES ✓	John DAY ✗	APPROVED
Joondalup	Emily HAMILTON ✓	Jan NORBERGER ✗	APPROVED
Wanneroo	Sabine WINTON ✓	Paul MILES ✗	APPROVED
Southern Rvr	Terry HEALY ✓	Peter ABETZ ✗	APPROVED
Cottesloe	Caitlyn COLLINS ✓	Colin BARNETT ✗	APPROVED
Burns Beach	Mark FOLKARD ✓	Albert JACOB ✗	APPROVED
Hillarys	Teresa RITCIE ✓	Peter KATSABANIS ✗	APPROVED

HELP STOP SUFFERING

Other electorate candidates responses (over 200) and for more information visit: www.FreedomofchoiceWA.com

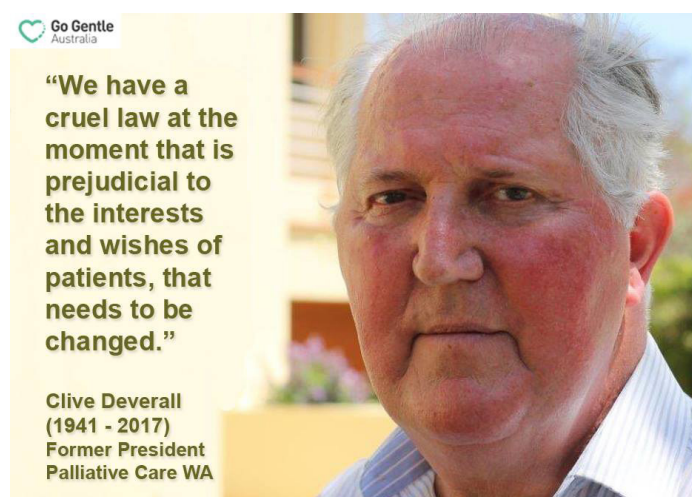
authorised by Dr ALIDA LANCEE Freedom of Choice WA Campaign, 553 South Western Hwy Byford 6122

Dr Lancee ensured that VAD was an election issue. Two weeks before the election, Premier Colin Barnett and Opposition Leader Mark McGowan made their election pitches to Christian voters at a packed forum hosted by the Australian Christian Lobby. McGowan said he hoped to have an honest and respectful relationship with churches and said that his support for voluntary euthanasia, for people who are terminally ill and in pain, was one topic some voters may not agree with him on.

Since the election of McGowan's government the incoming Health Minister, Roger Cook, has announced that he wants the WA public to have a considered and informed debate about law reform, and would welcome a Parliamentary Committee Inquiry in the lead up to drafting a VAD bill. In Victoria, the extensive preliminary work done by their Inquiry is considered to have built support for legislative change, and improved the chances of a VAD bill succeeding there.

Mr Cook said that while WA Labor will not introduce law reform as part of government policy (unlike the Victorian Labor government), the new WA government supported the tabling of a private member's bill. He added that Labor would allow MPs to exercise a conscience vote on this issue.

"Suicide is legal"



Clive Deverall, pictured, former Executive Director of the WA Cancer Council and former President of Palliative Care WA, took his life on March 11, the day of the WA election. He had suffered for two decades from a rare form of non-Hodgkin's lymphoma.

His widow, Noreen Fynn, told the ABC it was "no accident" that Clive took his life on the day of the WA election. "It was a message. If the legislation [to allow VAD] had been in place, I don't think he would have taken his life," she said.

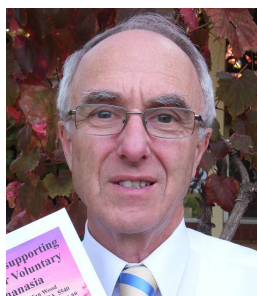
At his funeral, Clive's wife informed family and friends that Clive had left a suicide note that said "suicide is legal, euthanasia is not".

Described as "fearless and irrepressible", Deverall was a pioneer of cancer action, focusing on public health and prevention, support for patients and palliative care. In recent years, he became a strong advocate for legalising voluntary assisted dying.

In an interview last October, Deverall told the ABC that palliative care was not the answer for between 4%–8% of patients. He said: *“Certainly I still embrace what palliative care stands for, but even with their clinical guidelines, they avoid the elephant in the room which is the very end-stage patients, where symptoms cannot be controlled... The take home message is that we have a cruel law at the moment that is prejudicial to the interests and wishes of patients, that needs to be changed. The lack of compassionate law in this state will force some people into taking their own lives in a fairly brutal way.”*

In response to Clive Deverall’s suicide, Andrew Denton told ABC News: *“When the former President of Palliative Care WA takes his life in a public place in order to end his irreversible suffering and to protect his family from the same, it could hardly be more significant. It gives the lie to the line trotted out by politicians who oppose assisted dying laws, and their fellow-travellers in the medical profession, that ‘palliative care can take care of everything’. It’s not true. Clive, knew the realities better than anyone, because he was living and dying them.”*

Christians Supporting Choice for VE



Ian Wood

Adrian Price, a WA representative of Christians Supporting Choice for Voluntary Euthanasia (C4VE), was very busy in the build-up to the recent Western Australian (WA) election. Price emailed the 409 election candidates (for whom email addresses were available), asking for their position on the question whether “a terminally ill patient facing unbearable suffering should have the right to choose a medically-assisted death”.

Price received 225 replies, of which 201 (89%) supported choice. Nine respondents were either undecided or did not express their view. The 15 respondents who were opposed to choice came mainly from The Australian Christians Party and Family First.

Many of the written comments were extraordinary, and whilst space does not allow for all to be reproduced here, extracts from three have been reprinted below.

Greg Spaanderman, Australian Christians: *“I once had an uncle who rebelled against the Lord all his life. On his death bed he refused to acknowledge his sin and his Savior. God gave him time to repent but he refused. If he had been administered an assisted death, the time he had to repent would have been so much shorter. Euthanasia stops God’s work in all our lives at the time we choose rather than the time he chooses.”*

James Lawrence, Western Australia Party: *“....to dust we will return in GOD’s time! we also glory in our sufferings, because we know that suffering produces perseverance Only God knows what is best, and His timing, even in the matter of one’s death, is perfect.”*

Rosemary F C Steineck, candidate for South Perth, Australian Christians:

“The patient was a woman who was dying of a terminal cancer which could not be arrested by treatment. The cancer was a highly invasive spinal form of bone cancer which, as it progressed, caused her spinal bones to collapse onto the spinal cord, producing increasing agony which could not be palliated by normal pain relief. She was two months in dying. Why could not the doctor, with her permission, sever her spinal cord above the site of the cancer? She was dying anyway; there was no possible question of saving her life. Yes, she would have become a paraplegic. Yes, she would have been confined to a wheelchair. But would that really have mattered so much at the end of her life? She could have died pain-free.... There is not, in my view, a real need for assisted dying.”

I find these responses extreme, sickening, incredible and totally lacking in Christian compassion. It seems some ‘Christians’ would love to revert to the days of the Inquisition, and the burning of witches!!

Readers who do support compassionate Christian choice in dying are welcome to join our group by emailing ian.wood@christiansforve.org.au or writing to my address below. Membership is free.

Ian Wood

National Co-ordinator, Christians for VE Choice
Villa 1/4 Wills Place, Mittagong NSW 2575.

Mid-North Coast Group

The Port Macquarie group has had a name change to the Mid-North Coast NSW group, to reflect participation by people from areas up to two hours drive from Port Macquarie.

Following a major technical glitch in January, we have been busy rebuilding our database of supporter contact details and organising a new email address, which is pmq@dwdnsw.org.au. A lot of work and effort goes on behind the scenes, so a big thank you to our wonderful Leadership Team - Alana Hamilton, Cheryl Kelly, Paul Newman, and our new team member, Bev Hamilton-Fisher. Unfortunately, Bruce Gibbs has decided to use his energies elsewhere - we thank him for his considerable efforts since our inception.

Professor Ross Fitzgerald's presentation at our February meeting was very well received. Ross' demeanour and openness encouraged wonderful interaction and engagement. (The transcript is on the DWD NSW website for those who missed it). We were very excited to have our first DWD stall ever at the Port Macquarie Seniors Expo in early March. We met lots of great people and have added many to our email supporter list.

Our next group meeting is on 30 May. Guest speakers are life partners Susan Murphy and Graeme Atkins on 'Living and Caring with Alzheimer's and Other Dementias'. Susan was the full-time carer of her mother who had dementia by age 66, during which time Graeme was diagnosed

with *Younger Onset Dementia* at 54. In 2011, Susan was named the NSW "Caring Partner of the Year". Graeme has written many songs about his illness. This will be a meeting not to be missed!

Our quarterly meetings are held from 10 am till noon at 'The Pier', Port Macquarie Panthers Club, 1 Bay St, Port Macquarie (kindly provided at no cost to us). \$5 entry includes morning tea. Everyone is most welcome.

Annie Quadroy

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

Central Coast Group

At our first meeting of the year, we heard from Peter Cleasby, of the Central Coast Palliative Care Service, and Shayne Higson, spokesperson for Go Gentle Australia and DWD NSW. Shayne stepped in for Ian Wood, National Co-ordinator of Christians Supporting Choice for VE (C4VE), who was absent because of a family death in South Australia. Shayne explained the important role of C4VE in demonstrating to MPs that the majority of Australian Christians actually support VAD and that church leaders do not always represent the view of church members. Both speakers emphasised the importance of making an Advance Care Directive.

Volunteers to help with the activities of our group would be most welcome, so if you are able to help please speak to Annie Sobey, who has kindly agreed to be our new 'Volunteer Team Leader'.

Death of DWD ambassador, Anne Deveson and her daughter, Georgia Blain

Journalist and broadcaster, Anne Deveson, was a long-standing Ambassador for Dying with Dignity. In recent years, she was diagnosed with Alzheimer's Disease and eventually needed care, which was undertaken daily by her daughter, Georgia Blain. In early 2016, Georgia herself was struck down by a brain tumour that was removed, but then returned.

In October 2016 Georgia wrote about her mortality and her recent conversion to supporting VAD. Mother and daughter died within three days of each in December 2016, aged 86 and 51, respectively.



"Each morning when I wake at 4am, I am certain that this is the comfort I want. Whether or not I will choose to take it is another thing. But I want the choice to end my life on my own terms if I am still able." by Georgia Blain, Australian writer, living with a brain tumour. Photo by Steve Morenos Source: Herald Sun

The presenter at our next meeting on 19 May will be the The Hon. Trevor Khan MLC of the *NSW Parliamentary Working Group on Assisted Dying*, who will be speaking about the bill to be presented to the NSW Parliament later this year.

The following meetings will be on Friday 18 August and 24 November 2017. All our meetings are held in Meeting Room No. 3, The Hive, Erina Fair (opposite the Erina Library desk). Everyone is most welcome.

Bev Symons

Central Coast Group Coordinator
email: centralcoast@dwdnsw.org.au
phone 0413 376 343

Tasmania

The *Tasmanian Voluntary Assisted Dying Bill 2016* was introduced into Parliament in November 2016, and is due to be debated in May. Lara Giddings MP, former Labor Premier, who co-sponsored the bill with the Leader of the Tasmanian Greens, Cassy O'Connor, says much has changed since the failure of the previous bill, with much more momentum for change now.

International news

United States

Voluntary assisted dying (VAD) is now legal in the states of California, Colorado, Montana, Oregon, Vermont, Washington State and the District of Columbia which includes the nation's capital, Washington D.C.

Twenty four other states have introduced VAD bills since January 2017 - Alaska, Arizona, Connecticut, Hawaii, Indiana, Iowa, Kansas, Maine, Maryland, Massachusetts, Minnesota, Mississippi, Missouri, Nebraska, Nevada, New Jersey, New Mexico, New York, Oklahoma, Pennsylvania, Rhode Island, Tennessee, Utah and Wisconsin. We hope that many of these bill pass into law.

Supreme Court Appointee

Donald Trump's new appointee to the Supreme Court, Neil Gorsuch, is a known religious conservative and opponent of VAD.

In 2006 Gorsuch published a book on the subject, *The Future of Assisted Suicide and Euthanasia*, which cites Oregon law extensively. Gorsuch wrote that VAD laws would:

"tend toward, if not require, the legalization not only of assisted suicide and euthanasia, but of any act of consensual homicide" including "sodomasochist killings, mass suicide pacts, duels, and the sale of one's own life."



US President Donald Trump nominates Neil Gorsuch to be an associate Justice of the US Supreme Court at the White House in Washington, D.C., January 31, 2017.

In March this year The American Humanist Association joined 18 other organisations to express serious concerns with Judge Gorsuch's nomination to the Supreme Court. The letter's signatories comprise secular, ethnic, and community-based groups, who *"share a commitment to individual liberty and the separation of religion and government"*.

Time will tell how the appointment of Gorsuch will influence the future of VAD in USA.

Washington DC

As reported in our last newsletter, Washington D.C. passed the *Death with Dignity Bill* in November 2016. After the election of Donald Trump, a number of Republican Congressmen proposed legislation in the federal US Congress to overturn the law. Fortunately, their resolution did not come up for a vote within the statutory 30-day period, so the Washington D.C. assisted dying law became effective as of 18 February 2017.

Colorado

In December 2016 Colorado became the sixth American state to legalise VAD. Kathy Myers, long time sufferer of chronic obstructive pulmonary disease became the first publicly-known patient to end her life under Colorado's new law. Kathy had suffered serious health problems for decades, and as her condition deteriorated she became increasingly dependent on an oxygen tank to breathe. She spent the last eight months in hospice care.

After Colorado legalised VAD, Kathy and her husband began searching for the prescription that would end her life. It took them many months to find a doctor who would prescribe it.



Kathy Myers, pictured, was accompanied by her husband, their daughter and son-in-law, and the hospice nurse when Kathy took the medication. According to her husband:

"We held hands. She laid back on her pillow, and within about two minutes, her grip on my hand let up. And I looked up, and I never saw her take another breath. ... It was very quick ... very gentle."

Montana

In Montana, where VAD has been available since a 2009 court ruling, a group of conservative politicians attempted to overturn that ruling and introduce capital punishment for this crime. On 1 March 2017 by a narrow margin (a 50 to 50 tie vote) the Montana House rejected HB 536, that would have allowed the state to execute doctors for prescribing aid-in-dying medication.

Another bill, SB360, seeks to rule out patient consent as a legal defence, allowing the state of Montana to imprison doctors for writing a prescription for aid-in-dying medication for a terminally ill adult. SB360 is scheduled for a Senate Judiciary Committee hearing in late March.

Oregon

The Oregon Health Authority has recently published its report on the operation of its assisted dying regime. According to the report, 204 people received prescriptions under the *Death with Dignity Act* during 2016, and 133 people died from ingesting the medication.

Characteristics of these patients were similar to previous years: most were aged 65 years or older (80.5%) and had cancer (78.9%).

No referrals were made to the Oregon Medical Board for failure to comply with *Death with Dignity Act* requirements.

New Oregon bill

Oregon's Death with Dignity Act requires that patients receiving a prescription for life-ending medication are able to administer the medication to themselves. The Oregon Senate is currently debating Bill S.B. 893, which would only apply where a patient ceases to be "capable" of administering the lethal medication after it has been prescribed for the purpose of ending that patient's life in accordance with the *Death with Dignity Act*.

Under certain strict situations, this bill would allow "an expressly identified agent" (specifically nominated for that purpose in the patient's advance care directive, made at a time when they were competent) to collect the medication and administer it to the patient in the manner prescribed by the attending physician.

This bill has not received a lot of attention in mainstream media, but has been widely discussed in various global Christian forums, which claim that S.B. 893 is evidence of a 'slippery slope' from voluntary euthanasia to involuntary euthanasia and elder abuse. These comments are based on a misconception of S.B. 893, because the bill would cover only those who received approval for lethal medication while mentally competent, but deteriorated very quickly after receiving the prescription of the life-ending drug, and are then unable to administer it to themselves.

Hawaii

On 7 March 2017 Hawaii moved one step closer to being another US state to allow VAD, with the *Death with Dignity Bill SB 1129* passing in the State Senate by a margin of 22 votes to 3. Modelled on the Oregon's *Death with Dignity Act*, the bill was due to then be considered by the Hawaii State House. Unfortunately it was blocked by the House Health Committee, which effectively stopped the debate for this legislative session.

New Mexico

On 15 March 2017 the New Mexico Senate defeated a bill that would have legalised VAD for terminally ill people, expected to die within six months. In a 22-20 vote, seven Democrats joined 15 Republicans to stop the measure.

Canada

The Canadian VAD law came into effect in June 2016. It restricts assisted death to adults with a serious and incurable illness, disease or disability; who are in an advanced state of irreversible decline in capability and are experiencing intolerable physical or psychological suffering. Further, their death must be reasonably foreseeable. In Canada VAD is known as medically assisted dying or MAID.



Noreen Campbell with her horse, Dasha.

On 12 January 2017 Noreen Campbell accessed an assisted death, dying peacefully in her sunroom with the help of a physician. She died in the company of her loving family and close friends. Noreen suffered from aggressive oral cancer before developing chronic obstructive pulmonary disease. Noreen was among the first in Canada to be approved for VAD, submitting her application the day after the federal government legalised it.

In the time between the approval of her request in August 2016 and her peaceful death on January 12, 2017, Noreen Campbell worked closely with *Dying With Dignity Canada* to create the 'Noreen Speaks' video series. Jeffrey Brooks, who produced the series of videos with Noreen was so inspired by her example that he penned a letter shortly before she died, ending with: *'In a perfect world, she would be well and not dying this week. She would not suffer from a terrible disease that qualifies her for MAID. But we don't live in a perfect world and she will die. She chooses to die this week, at home, with her family at her side and her horse looking on. Choices. It is all about making choices with what you have.'*

Many VAD advocates are arguing that the new law is too narrow in scope, because it requires that death be 'reasonably foreseeable'. Some believe that the law is unconstitutional, as it does not conform to the Supreme Court's decision. They point to cases of patients with incurable, degenerative diseases, who are experiencing hopeless and unrelievable suffering, but who are ineligible under the new law. On the other hand, many doctors are complaining that the new law is too broad because the term "reasonably foreseeable" is imprecise. Some are taking it upon themselves to interpret this to mean death within six months. Another difficulty has been the reluctance of some anti-VAD doctors and institutions to cooperate with the law.

A major contributor to the dissatisfaction with the operation of the new law was the short period within which the laws were introduced. This was due to the 12 month deadline imposed by the Supreme Court's ruling in February 2015. The then conservative Harper government embarked on delaying tactics. It was not until after the election of Justin Trudeau's government in mid-2015, that plans for implementing VAD finally began. The court extended the deadline, but the law was still introduced hurriedly, before there was general agreement and clarity about its implementation.

The lesson for any Australian parliament contemplating VAD legislation is that, in addition to passing a law, there must be substantial planning and cooperation with medical groups in the lead-up to its implementation. This approach is being followed in Victoria, where a panel established by the Andrews' government is consulting with experts and key stakeholders in developing recommendations for the assisted dying law and how it can best operate.

Terminally ill man begins challenge to UK law



Noel Conway, with wife Carol at home in Shropshire, England.

Noel Conway, retired college lecturer, was diagnosed with Motor Neurone Disease in November 2014. His condition is incurable and at age 67 he is now not expected to live beyond six months.

Before his illness Noel enjoyed hiking, cycling and travelling. Whilst he retains full mental capacity, his deteriorating condition means that his ability to move, dress, eat and deal with personal care independently has diminished considerably.

Noel is now dependent on a ventilator to breathe overnight and much of the day, as his breathing muscles continue to weaken. Noel fears that without a change in the law he may be forced to suffer against his wishes.

Noel is bringing his case to court to fight for the option of an assisted death now when he is in his final six months of life. Explaining his decision to pursue the case, Noel said: *"I feel very strongly that it is a dying person's right to determine how they die and when they die. The current law denies me this right. Instead I am being condemned to unbearable suffering in my final months. I may die by suffocation or choking, or I could become completely unable to move or communicate. The only way for me to have some control is to refuse use of my ventilator, but there is no telling how long it would take for me to die, or whether my suffering could be managed."*

"I'm going to die anyway. It's a question of whether I die with or without suffering and on my own terms or not. I'm bringing this case not just for me, but for all others facing terminal illness who want and deserve to have the option of a safe, dignified assisted death available to them in the UK."

Supported by UK advocacy organisation Dignity in Dying UK, Noel has instructed a law firm to seek permission for a judicial review in the High Court, on the grounds that the current law contained in the *Suicide Act 1961* is incompatible with his right to a private life, which includes being able to make decisions about how his life ends. The case will present evidence on the eligibility criteria and clear safeguards that could form part of a workable legal framework on assisted dying. If permission is granted, there will be a full hearing of the case in the High Court later this year.

An earlier British case brought by Tony Nicklinson, who suffered from paralysis after a stroke, was dismissed by the Supreme Court in 2014, with judges stating that it was important that Parliament debated the issues before any decision to change the law was made by the courts. Conway's case is different to the Nicklinson challenge in that Noel has a terminal illness and his legal team are setting out strict criteria and clear safeguards to protect vulnerable people from any abuse of the system.

On 22 March 2017, Richard Gordon QC opened his argument for the High Court to consider Conway's case by saying that if Parliament did not deal satisfactorily with the issue of assisted dying, then the courts must look at fresh evidence. According to Gordon QC, the last time parliament debated a private member's bill on assisted dying it only gave four hours to the issue. *"Parliament had not moved an inch yet one can see the way society is moving"* said Gordon.

The judges reserved their decision, which will be provided soon, due to Noel Conway's circumstances.

Germany

While we were busy focusing on the Canadian Supreme Court's decision to instruct their Parliament to legalise VAD, it seems we missed an important development in Europe that was happening at the same time. In 2015, Germany passed a new bill to legalise VAD, as long as it is performed for altruistic motives. (The German law in this area had previously been unclear, as VAD was neither permitted nor banned prior to the enactment of this bill). The new law means that family members and doctors who provide assistance do not need to fear prosecution, as long as there is no profit motive involved.

Adoption of this law followed heated debates in the German Parliament. At least four draft bills seeking to legalise or ban VAD were proposed by cross-party groups, with the 'middle' version ultimately being passed. The final bill was supported by all parties, including Angela Merkel's Christian Democrats, and the opposition Left Party.

Under the new law it is illegal to assist someone, including a doctor, to end the person's life for a "profit motive", with penalties of up to 3 years imprisonment. Former Justice Minister Brigitte Zypries said the measure "*will open an era of great legal uncertainty*" as "*when does a doctor behave in a business fashion? ... That is unclear.*"

German federal court rules on access to lethal medication

A new ruling by the Federal Administrative Court of Germany has reignited discussion about VAD. The case concerned Bettina Koch who had an accident that left her completely paralysed, reliant on a ventilator and constant nursing care. She suffered from chronic pain and cramping. In 2002 she asked The German Federal Institute for Drugs and Medical Devices to provide her with medication to enable her to die, but the Institute refused. In 2005, Mrs Koch ended her ordeal in an assisted death at Dignitas, Switzerland. Before leaving for Switzerland, she commenced litigation, which was continued by her husband after her death.

After many years of further unsuccessful court hearings, Mr Koch finally took the case to The Federal Administrative Court of Germany. In March 2017, this court issued a landmark decision - that

under specific exceptional circumstances, the German state cannot refuse to give life-ending medication to a person who requests it. It stated that the German Constitution created the '*right of a severely and incurably ill patient to decide how and at what time their life should end, provided that they are in a position to make up their own mind.*'

The court found that, even though purchasing a narcotic substance for the purpose of suicide was generally not allowed, there had to be exceptions. For example, if a severely and incurably ill person, with unbearable suffering, freely and seriously decides to end their life, when there are no reasonable alternatives, such a person should be permitted to access prescribed narcotics for a dignified and painless death.

This ruling, together with the 2015 law passed by the German Parliament, paves the way for greater access to VAD for the German people. We await news of how these laws are operating in practice.

VAD for Italian celebrity



The campaign for VAD recently received substantial publicity in Italy following the death of much loved Italian disc jockey, Fabiano Antoniani, pictured. Antoniani, who had a catastrophic accident three years ago, which rendered him blind and quadriplegic. He has endured painful treatments, with limited success, and publicly campaigned for his right to an assisted death in Italy.

In late February, Antoniani travelled to Switzerland, where he ended his life by lethal injection at Dignitas, surrounded by family and loved ones. Prior to his death, Antoniani issued a statement: "*Finally I have managed to arrive in Switzerland. I have arrived alone, without the help of the State. I will be relieved soon from this hell of pain.*"

Marco Cappato, pro-VAD campaigner and an ex-member of the European Parliament, accompanied Antoniani to Dignitas.

continued overleaf

Cappato presented himself to the police upon returning to Italy and has been indicted to possibly face trial and up to 12 years imprisonment for assisting the suicide. This has reignited the Italian debate about laws on VAD, with moving tributes to Antoniani and Cappato in print and social media. Italian legislators have responded by agreeing to expedite law reform to clarify end-of-life issues.

Assisted Suicide: The Musical by anti-VAD disability activist

Assisted Suicide: The Musical is a musical based on opposition to voluntary assisted dying (VAD). It is currently performing in London and will be coming to Australia later this year. The show is written and performed by disability activist, Liz Carr, who suffers from a severe genetic disorder that prevents her from extending her muscles, among other impairments.

In an interview published in *The Wall Street Journal*, Carr states “We’ve become used to clapping along and thinking that choice is good ... [we don’t even realise] that we’re essentially we asking the state to be involved in people’s death.”



According to Ms Carr, pictured, the aim [of VAD] is to normalise a choice that was unthinkable a generation ago, with the result that people like her would feel compelled to conclude: “You know what, my life isn’t worth living.”

She also claims that the main watchword of the VAD movement is ‘dignity’. The truth, she insists, is that “your state of health, mental or physical, has no bearing on your dignity.” If voters and lawmakers take the view that dignity derives from good health and ability, then all sorts of weak and vulnerable people can be discarded, she claims. Hence her musical provides the message: ‘I’m disabled, but who are you to say I lack dignity?’

There are a number of flaws in Ms Carr’s arguments, including the conclusion that VAD sends a message to people with disabilities that their lives are not worth living. The right to access VAD should not be based on one’s physical abilities or disabilities, but on the degree and persistence of one’s suffering. DWD NSW believe that VAD should be available to individuals who face unrelievable suffering from either a terminal or incurable illness, that is making their life unbearable.

Further, there is no evidence that in jurisdictions where VAD is legal, people with disabilities feel devalued or encouraged to end their lives. Research conducted by Dr Linda Sheahan, palliative care specialist and opponent of VAD, found no increased incidence of VAD among people with disability in jurisdictions where it is legal. The Victorian Parliamentary Inquiry into End of Life Choices also found no evidence of institutional corrosion or the often cited ‘slippery slope’.

Empirical data from countries where VAD is legal confirms that the vast majority of people requesting VAD have a terminal illness, most often cancer or progressive neurological diseases. In most of these countries, people with disability do not qualify for VAD, unless they have a terminal illness. Even in Belgium and Holland, which have the most liberal interpretation of the law, access to VAD amongst people with disability is extremely rare.

In addition, surveys of disability groups have repeatedly found that the majority want the right to access VAD. This includes a recent North American study of people with Multiple Sclerosis, where 65% stated they would consider VAD in specific circumstances. Some argue that to deny people with disabilities the right to VAD is a form of discrimination which disadvantages their group.

Ultimately good laws should aim to find a balance between all the interests involved. Whilst the rights of people with disabilities should be protected, so should the rights of people who are hopelessly ill, who want the reassurance that they will not have to suffer indefinitely. We totally agree with Liz Carr that disability does not equate to lack of dignity. Indeed, the main issue that VAD laws seek to control is not lack of dignity, but relief from suffering. In some cases, suffering may include the indignity associated with loss of bodily functions at end of life, but it is actually the suffering, both physical and existential, that is the critical issue.

NEW BOOKS

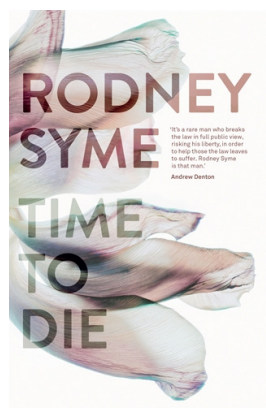
Time to Die by Dr Rodney Syme

Dr Syme's new book, *Time to Die*, is essential reading for anyone following the Voluntary Assisted Dying (VAD) debate in Australia. As in his previous book, *A Good Death* (2008), Dr Syme draws on his many years counselling dying patients. In some cases, as he has stated on national television, he personally enabled people to die at the time and place of their own choosing. *Time to Die* explores the notion of dignity in some detail, and discusses what we mean by 'existential suffering'.

Dr Syme makes a persuasive case that any legislative framework for assisted dying in Australia should cover not only the terminally ill, but also those who are suffering from what he calls 'advanced incurable illnesses', such as Motor Neuron Disease. He argues for this in a compelling chapter, which analyses the notion of suffering, with reference to religiously-inspired ideals.

Time to Die brings readers up-to-date with the state of the VAD debate in Australia, with particular focus on the *Victorian Parliamentary Inquiry into End-of-life Choices* and the subsequent draft bill to legislate assisted dying.

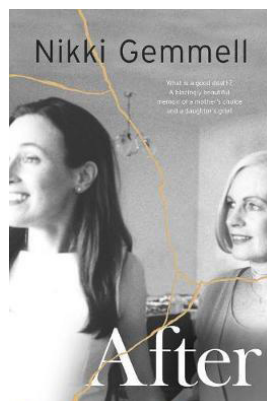
Journalist, Miriam Cosic, reviewed *Time to Die* in *The Weekend Australian* on 25 March: "His writing is cool, elegant, scientifically precise and yet immensely moving...This makes the driest of subjects, technical or legal, interesting and understandable, and makes the book a much-needed addition to the political debate about legalisation.... In his previous book, 'A Good Death', Syme made a strong and careful argument in favour of assisted death. The new one is more personal, more philosophical, more lyrical, and so more powerful."



Time to Die can be purchased from Dying With Dignity Victoria (see Resources–Public at www.dwdv.org.au) or through selected bookstores and online book retailers. It is also available as an e-book.

After by Nikki Gemmell

After by author and columnist (News Limited), Nikki Gemmell, is a reflection on the suicide of her mother, Elayn, who suffered unbearable pain and disability. Elayn's suffering started with a foot operation that went wrong, leading to spinal problems, and then addiction to pain-killers. On an evening in October 2015, Elayn, alone in her home, consumed alcohol with the drug 'Nembutal'. She was found dead the following day, by tradesmen.



After provides a powerful argument in favour of VAD, because it discusses the grief and shock experienced by loved ones after a suicide taken to end suffering. Whilst Elayn would not have qualified for an assisted death under the laws currently proposed in

Australia (as her illness was not terminal and she may have been clinically depressed), if a VAD law was passed, people like Elayn would have more confidence to speak to their doctor and loved ones about their desire to end their suffering by death.

Much of the book deals with the author's troubled relationship with her mother. Miriam Cosic also reviewed *After* in *The Weekend Australian* on 25 March: "Nikki Gemmell's memoir of her mother, who committed suicide rather than endure physical disability and pain, couldn't be more different to Syme's book. It is not the cool professional's appraisal but one long cry of pain for traumatic loss."

The book is enriched by the inclusion of a large number of the personal letters of suffering that Gemmell received after she wrote about her mother's death in her column in *The Australian*.

The subject-matter of *After* was explored in a recent ABC *Australian Story* program, where Nikki Gemmell recounted learning of her mother's suicide: "I was just a mess, just so floored and shocked and devastated. The male police officer had taken out his notebook, and he was taking notes of what I was saying. ..And it gradually dawned on me that perhaps they were seeing if I was implicated in the whole thing too.... it was such a bleak and lonely death, we as a family would have just wanted to be there to hold her hand."

Increasing access to legal assisted dying



By end of 2016, close to 200 million people lived in places with some form of legal assisted dying. In the last two years, this figure has increased very dramatically.

- Switzerland (Criminal Code 1942)
- Netherlands (2002)
- Belgium (2002)
- Luxembourg (2009)
- Colombia (2015 – court decision)
- Germany (2015)
- Canada (2016)
Quebec Province (2014, came into operation Dec 2015)
- US
Oregon (1997)
Washington (2009)
Montana (2010 - Court decision)
Vermont (2013)
California (2016)
Colorado (2016)
Washington DC (2016)



Australia had the world's first assisted dying law in the Northern Territory (1995) but only 4 people were able to use it before it was overturned by the Federal *Euthanasia Laws Act 1997*. Now close to 200 million people live in places with access to legal assisted dying but not Australians.

DYING WITH DIGNITY NSW 2017 Annual General Meeting

Saturday 27 May 2017 from 1.00 pm to 3.30 pm

Mitchell Theatre - Sydney Mechanics' School of Arts

Level 1, 280 Pitt Street Sydney (accessible access)

(located on the Eastern side of Pitt St between Park and Bathurst Streets)



Guest Speaker: Professor Colleen Cartwright

‘End of Life Options – The Key Issues’

Professor Cartwright PhD was Foundation Professor of Aged Services and Director of the Aged Services Unit at Southern Cross University. Professor Cartwright designed the Advance Health Care Directive and Enduring Power of Attorney forms that are used widely across Australia.

Please come along and bring your friends and family too.

This event is FREE. Afternoon tea is provided so please RSVP via email to dwd@dwdnsw.org.au or phone 02 9212 4782

Dying with Dignity NSW (DWD NSW) is an advocacy organisation pursuing a change in the law that will enhance choice at the end of life. Our activities include lobbying politicians; liaising with media, building alliances; running pre-election campaigns; creating and promoting videos of personal stories; increasing public awareness through workshops and forums; sharing news of Australian and global developments; encouraging discussion of end-of-life preferences and provision of advance care planning forms to members.

website www.dwdnsw.org.au

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