



WINTER 2017

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Allow me to die peacefully.

Support Annie's right to choose.



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President's message



We have been extremely busy in the last few months, meeting with NSW Members of Parliament (MPs) and key influencers, preparing information packages and planning strategies for persuading undecided MPs to support the NSW *Voluntary Assisted Dying Bill*. From our various conversations, it looks like the numbers in the Parliament's Upper House are very close. We have heard *"this is an issue whose time has come"* from more than one MP, and there is a feeling that the tide is turning.

Meanwhile our opponents have stepped up their campaign of fear, misinformation and spin. Christian organisations like Right to Life and the Australian Christian Lobby are warning of near apocalyptic consequences should a voluntary assisted dying (VAD) law be passed, and devout religious leaders are coordinating letter writing campaigns to MPs during Sunday service.

It is exciting to see Victoria come one step closer towards passage of their government-sponsored VAD bill. The Victorian Ministerial Advisory Panel on Voluntary Assisted Dying, led by Dr Brian Owler, has released its recommended framework for Victorian legislation. This will be incorporated into the bill, which is expected to be debated in both houses during September. Already Christian opponents are up in arms, with the largest provider of palliative care facilities in Victoria announcing that they will refuse to allow their staff to participate if the law is passed. Meanwhile, Right to Life have been letterboxing residents in marginal seats, and vowing to target MPs who dare to vote in favour of the Victorian bill, in next year's state election (see pages 7 to 9 for more).

Andrew Denton and his organisation, Go Gentle Australia (GGA), have been focusing their energies on the Victorian campaign. They have been doing a huge amount of work behind the scenes, meeting with MPs and liaising with the advisory panel. Who could believe that the man with seemingly boundless energy who spearheaded this campaign

could be afflicted by serious heart disease? You have no doubt heard by now that Denton has undergone multiple bypass surgery and is currently recovering in hospital. The team at GGA have reassured us that their work will continue, and Denton anticipates rejoining the campaign in early September with a clean bill of health and "an exciting new scar". All of us at DWD NSW wish him a speedy recovery.

While Victoria is seen as the great hope, don't write off NSW! From our conversations with MPs, we believe the NSW bill has a real chance of passing in the Upper House. The final vote will be close, and our job is to persuade the few undecided politicians to get it over the line. We don't yet have enough information about how Lower House members are positioned, but we have received positive messages from some of the MPs that we have approached, and others that our members have engaged with.

Thank you to all DWD NSW members who have written to their local MPs urging them to support the bill, and who have forwarded their responses to us. This information helps us to track MPs who are definite supporters and opponents, and enables us to identify the undecided MPs that we need to talk to. Engaging with Members of Parliament is the single most important thing that you can do to help this bill to pass. In addition to Lower House MPs, it is now time for us to start writing to members of the Upper House (see details on page 3).

A very exciting recent development was the passing of a motion by the NSW Nurses and Midwives Association on 20 July to support the introduction of VAD in NSW (see page 6).

Readers will remember the personal crusade led by terminally-ill Victorian man, Peter Short, in his dogged pursuit of legislative change. The excellent documentary, *Fade to Black*, based on Peter's campaign, being screened across NSW (see page 16).

Finally, a huge thank you to those of you who made donations to help us with the current campaign. If you have not yet done so, please consider contributing to our fighting fund at this critical time. Donations can be made through our new DWD NSW website or via the form on page 14.

As always, thank you for your support.

Sarah Edelman
President, DWD NSW

NSW VAD Bill 2017

On 16 May *The Voluntary Assisted Dying Bill 2017*, drafted by the NSW Parliamentary Working Group on Assisted Dying (PWGAD), was unveiled for public consultation. The bill is the result of two years' consultation by the group, comprising Trevor Khan MLC (Nationals), Lee Evans MLA (Liberal), Alex Greenwich MLA (Independent), Lynda Voltz MLC (Labor), and Mehreen Faruqi MLC (Greens).

The closing date for submission of feedback has passed, and the PWGAD is now undertaking the mammoth task of going through all submissions and considering further changes to the draft bill. They will take on board suggestions they believe will strengthen the bill, that should be ready to be debated in the NSW Upper House in September.

We have been advised that it is now time for our members to write to Upper House Members of Parliament (MPs) urging them to support the bill. The Upper House comprises 42 members from various political parties. Unlike Lower House MPs, these members are not directly accountable to a particular geographical area, but jointly serve all of NSW.



Please choose some Upper House MPs (as few or as many as you like from the following list) and send them individually handwritten letters. Ideally, we would like these letters to arrive over August and September, in the period leading up to the debate (rather than all at once now).

Following is a list of all the MPs in the NSW Upper House. Their address is NSW Parliament House, 6 Macquarie Street, Sydney, NSW, 2000.

SHOOTERS AND FISHERS	
Robert Brown	Robert Borsak
ANIMAL JUSTICE PARTY	
Mark Pearson	
NATIONALS	
Niall Blair	Richard Colless
Ben Franklin	Bronnie Taylor
Sarah Mitchell	Wes Fang
Trevor Khan	
LIBERAL	
John Ajaka	David Clake
Greg Pearce	Lou Amato
Scott Farlow	Don Harwin
Shayne Mallard	Peter Phelps
Matthew Mason-Cox	Catherine Cusack
Taylor Martin	Scott McDonald
Natasha MacClaren- Jones	
LABOR	
Daniel Mookey	Greg Donnelly
Moselmane Shaoquett	Adam Searle
Walt Secord	Ernest Wong
John Graham	Courtney Houssos
Mick Veitch	Peter Primrose
Lynda Voltz	Penny Sharpe
GREENS	
(party policy of support for VAD)	
Jeremy Buckingham	David Shoebridge
Justin Field	Dawn Walker
Mehreen Faruqi	
CHRISTIAN DEMOCRATS	
(party policy of opposition to VAD)	
Fred Nile CDP	Paul Green CDP

Debunking the myths

Download PDF here...



Shayne Higson, our DWD NSW Vice-President, has put together an excellent document to inform politicians and dispel some of the myths that are propagated by the opponents of voluntary assisted dying.

It is called *Assisted Dying: Setting the Record Straight* and is available on our website – see this image on the top of our website news page.

You may find it a handy reference if you find yourself in a conversation with a person who mistakes these myths for facts.

Community Consultation

In collaboration with Dying with Dignity NSW, the Parliamentary Working Group on Assisted Dying (PWGAD) has been conducting community information and consultation sessions since the release of the *NSW Voluntary Assisted Dying Bill*.

On 13 July, Alex Greenwich hosted an excellent forum in the NSW Parliament House to discuss the bill. The meeting was chaired by Alex Greenwich MLA. The panel of speakers comprised Trevor Khan MLC, Coral Levett (President of NSW Nurses & Midwives' Association), Linda Scott (City of Sydney Councillor), and Sarah Edelman (DWD NSW). The video of the whole forum and the transcript of Coral Levett's speech is available on our website.

Trevor Khan MLC also held a forum in Port Macquarie (more details provided in the Mid-north Coast Group report on page 13).

Similar community forums, hosted by Lynda Voltz MLA, are planned for other areas of NSW:

Saturday 12 August at 2 pm at St Georges Basin Country Club (11 Paradise Beach Rd Sanctuary Point)

and

Friday 25 August at 11 am in the Tuncurry Beach Bowling Club (Meeting Room 21 Parkes St Tuncurry).

A number of MPs from the Lower House have started consulting with constituents, to find out their view on the bill. Some, like Liberal Dubbo MP Troy Grant, and Nationals Northern Tablelands MP, Adam Marshall, have set up surveys on their website for constituents to complete. Others, like Liberal member for Kiama, Gareth Ward, have organised public meetings of their constituents to enable face-to-face consultation on the issue of voluntary assisted dying (VAD).

What is clear is that MPs are engaged on this issue, and some are genuinely thinking about how they will vote.

Members of the DWD NSW board have met with several MPs, and we have received helpful feedback. At the same time we have been providing MPs with information packages that they can use in planning speeches for the Parliamentary debate, and for countering misinformation that will be promoted by opponents.

Letter from Annie G – the face of our campaign

Most members will recognise Annie G from the video that has been shared on Facebook, and viewed by nearly 230,000 people. Please sign her petition if you have not done so yet at www.change.org/annie.

Annie has motor neurone disease, and the petition that accompanies the video, calling on politicians to pass the *NSW Voluntary Assisted Dying Bill*, has been signed by over 95,000 supporters. At the time the video was made (in February this year) Annie was still able to speak; however she has now lost that ability, and communicates by typing with one finger. Sadly, Annie is gradually losing her functional abilities.



Annie's plight has become a symbol of the campaign to legalise VAD in NSW. We are extremely grateful to Annie and her family for agreeing to speak publicly about their situation. They have agreed to visit and talk to MPs on why they want the NSW bill passed. This will include NSW Premier, Gladys Berejiklian, who has agreed to meet with the family in the lead-up to the bill being presented in Parliament. We suggested that Annie might like to write an update on how she is faring. Below is her letter to our members, written in mid-July.

Hi All,

I'm not so good. I sleep in a mask connected to a bi-pap machine that regulates my breathing – not sexy, but I'm sleeping better now. My left arm won't work anymore and I am losing my right arm. This disease is a bastard!

I can't write or sign. I can still walk, but not too far.

I can still laugh and make love!

I have a carer who comes in for two hours, four days a week. I can't make my breakfast or towel myself after a shower. It is cold in the mornings in my Blue Mountains home. I can't dress myself or drive anymore.

We have a new bathroom to make space for a wheelchair (the National Disability Insurance Scheme (NDIS) didn't come to the party) and we have a fight on our hands for the three lifts we need to put in so that I can get around at home (we're waiting on the NDIS to review the decision). We have changed the sliding doors so it hasn't a lip, and have built a ramp outside. I'm planning on working on that till the end of the year!

In June, we caught the Indian-Pacific to Perth and stayed in the Margaret River district for five days, tasting wine. Rottnest Island was our last exploration! (bucket list time). Life is good with support!

I'm still working at the Royal Institute of Deaf and Blind Children two days a week - one day in the office and one at home. Paul (my husband) drives me in.

My daughter, Eleni, will be 21 next month and my sons, Michael and Christopher and will be 32 soon. My daughter-in-law is pregnant and due in November! I'm going to be 'Ma' and Paul can be whatever he wants.

I dearly miss talking to my husband and children, singing to radio, or yelling. My husband is my greatest ally, advocate and lover. Even though I can't speak, he waits while I type out a message. I'm getting a trial of eye gaze technology this Friday, so when I lose my ability to use my hands, I will still be able to communicate using my eyes. The technology enables the user to operate a laptop computer or speech generating device.

We are buying a really good running wheelchair so Paul and I can walk like we used to. Every day up at 6 am to walk 3 kms. We both miss our walks in the mornings. Paul is a runner, so we have roped in lots of family and friends to join us on this year's City to Surf. We'll be walking it though!

I have made contact with Trish Doyle, my local MP and we are making a video together, urging MPs to support the coming Voluntary Assisted Dying Bill.

Please handwritten letters to your local MPs.



politicians like me just cannot let terminally ill patients live in chronic pain and continue to suffer

Trish Doyle, Labor Member for Blue Mountains, and Annie making a short video for Change.org on 26 July, 2017.

I'm really looking forward to meeting the Premier, Gladys Berejiklian, with my neurologist, Professor Dominic Rowe, who has agreed to come with me.

I hope I can make a difference to the campaign. I want to see the NSW Bill passed.

Thank you to everyone for your good wishes, Annie.

Annie, with about 30 family, friends and supporters, will be participating in the City to Surf on Sunday 13 August to help raise awareness of VAD. The team will be walking wearing T-shirts marked 'Annie's Choice' and 'Dying with Dignity NSW'.



Luke Cornish, the brilliant filmmaker who made the video of Annie's story earlier this year, plans to film a second (shorter) video update, including the team's participation in the City to Surf.

New poll finds that most doctors and nurses support VAD Bill

Annie G's great work for DWD NSW has included crowdfunding to pay for an opinion poll of medical professionals. In June Annie wrote to the thousands of people who signed her petition on Change.org and raised sufficient funds to conduct a poll of doctors and nurses.

The poll was conducted by independent market research company, Ekas, who surveyed over 4000 health professionals for their view on the draft NSW Voluntary Assisted Dying Bill.

Of the more than 500 doctors who responded, 60% stated that they support the bill, whilst fewer than 30% opposed it. (An earlier survey conducted by *Australian Doctor* last year found that 65% of doctors supported a change to the law).

A smaller Ekas poll of 100 nurses found even stronger support, with 80% in favour and fewer than 10% opposing.

These results are in contrast to the 2016 survey of doctors conducted by the Australian Medical Association (AMA), that indicated 50% of doctors thought that medical professionals should not be involved in voluntary assisted dying (VAD), while 38% believed that they should, and 12% were undecided. The AMA is the country's peak medical body, although only about 30 % of Australian doctors are members. The AMA generally takes a conservative approach to health policy. It has actively campaigned against assisted dying legislation for many years, and launched strong opposition to the South Australian bill that was defeated in late 2016. However, it is significant that the Victorian branch of the AMA has decided not to campaign against the Victorian bill.

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Doctors for Assisted Dying Choice (Drs4AD) is a national group of Australian doctors, representing most medical specialties, who are committed to supporting legislative change on VAD. According to the NSW Convenor, Dr David Leaf, the role of Drs4AD is that of providing unbiased medical opinion on matters relating to assisted dying to the media, medical profession, politicians and the public. They have recently completed submissions on the Tasmanian, Victorian and NSW VAD Bills.

Survey: breast cancer patients support VAD



More than 10,000 Australians who are living with, or are survivors of, breast cancer contributed to a survey commissioned by Breast Cancer Network Australia (BCNA) in the first half of 2017. Three-

quarters of respondents said they were supportive of people having access to VAD. The BCNA survey also showed that the longer the person had been living with metastatic cancer, the more supportive they were of VAD. Ninety six percent of people with metastatic breast cancer for five or more years were found to be in favour of legal change.

NSW Nurses and midwives support VAD

It is official - members of NSW Nurses and Midwives Association (NSWNMA) support the introduction of voluntary assisted dying (VAD) laws. On 20 July a motion to endorse their *Position Statement on Assisted Dying* was passed almost unanimously by 500 delegates at the NSWNMA Annual Conference. Item 12 of the statement says "We support legislative reform so that persons with a terminal or incurable illness that creates unrelieved, profound suffering shall have the right to choose to die with dignity in a manner acceptable to them and shall not be compelled to suffer beyond their wishes."

Representing more than 259,000 nurses and midwives across NSW, the NSWNMA statement adds weight to the community support for this issue.



The press release issued by the NSWNMA quoted President, Coral Levett (pictured), saying "We represent a very diverse membership and we strongly believe that nurses, midwives and assistants in nursing are entitled to their own opinion, however, we also acknowledge that people with a terminal or incurable illness should have the right to choose to die with dignity. Seven countries around the globe have legalised assisted dying and this empowers over 100 million people with the full choice about what happens to them at the end of their life. Currently, not one Australian is afforded this choice and that is why legislative reform is so important."

Nurses have direct and ongoing contact with people in the final stages of their lives, giving them a unique position to observe the impact of our current laws. Coming just a few months before the VAD bill will be introduced in the NSW Parliament, their support adds weight to the argument that our current laws are inadequate. As one of the most trusted professions, the pronouncement of support by the NSWNMA is significant and adds gravitas to the argument for law reform to provide VAD.

Victoria's expert panel

On 21 July, The Victorian Ministerial Advisory Panel, an independent panel of experts, released its final report, based on the 14 public forums and 176 submissions made to the panel's public discussion paper. Its final report contains 66 recommendations for law reform (see page 9 for specific details).

It is anticipated that these recommendations will now be incorporated into the Victorian bill, which is expected to be debated during September. If the bill is passed terminally ill Victorians will be able to apply for assistance to die from 2019.



Neurosurgeon and immediate past President of the Australian Medical Association (AMA), Professor Brian Owler, (pictured) headed the expert panel. His senior

role within the medical establishment has given the Victorian taskforce credibility. Owler was quoted as saying: "My knowledge of the AMA, of how medicine works, can be an advantage in making sure the legislation can be as good as it can be, in terms of not only supporting patients but also supporting medical practitioners as well."

While most of the Victorian Government Cabinet Ministers are in favour of the bill (including Premier Daniel Andrews (pictured), Health Minister Jill Hennessy and Attorney-General Martin Pakula), others like Deputy Premier James Merlino are not. To our great disappointment, the Deputy Premier publicly spoke out against his government's bill, saying "This bill endorses suicide, which is a line I don't think our society should cross."



Liberal Opposition Leader, Matthew Guy, is also opposed to the bill, but says he will allow a conscience vote for his party. A handful of Liberal MPs have come out in favour of the bill.

Most Victorian MPs have not yet declared their position.

In an interview with *The Australian* on 13 July, Former Victorian Labor Premier, Steve Bracks, revealed that he was a longtime supporter of VAD. He said he did not propose reform while he was in power (between 1999 and 2007) because the timing was not right. Mr Bracks was regarded as a social conservative during his time in politics. His support follows that of political rival Jeff Kennett, Liberal Premier from 1992 to 1999, who has also backed the Victorian government's push to legalise VAD.

The vote is widely expected to pass the Victorian Upper House, where it will be debated first. However, the outcome is expected to be much closer in the Lower House. With the state election just over a year away, Victorian politicians in marginal seats are nervous about a possible backlash.

The Australian Christian Lobby's Victorian director, Dan Flynn, is marshalling his 12,000 supporters to lobby their local MP in a grassroots campaign against the VAD bill. Flynn was reported in *The Saturday Paper* (5 August) as saying "When you pick a fight with ethnic communities and faith-based communities over a social policy issue like this, it's likely to have electoral ramifications and all MPs are open to this."

According to *The Guardian* (27 June), Right to Life is targeting key marginal Victorian seats, dropping vexatious leaflets that ask whether Andrews is "trying to save healthcare dollars?" According to *The Saturday Paper* (5 August) the 260,000 flyers read "Remember the life you save may be your own," and urges householders to contact their local MP to protest plans to "legalise government-sanctioned suicide by doctors for the sick and infirm".

According to *The Age* (5 August), "the biggest combatant of all is the Catholic Church." On April 18, Archbishop Denis Hart (pictured) wrote 'A Pastoral Letter to the Catholics of Victoria', co-signed by his bishops, saying: "We should be clear – there is no safe way to kill people or to help them to their own suicide. For millennia, the Church and civil society has understood such actions to be morally and ethically wrong. The commandment, 'Thou shalt not kill' is both a biblical and civil dictum and should remain so for very good reason..... If you would like to



contribute to the efforts of your local parish, ask your parish priest how you can be involved.” According to *The Age* (5 Aug), The Catholic Education Office passed that document on to its Victorian schools and some are now getting politically active in opposition to the VAD bill.

Proponents of the bill are cautiously optimistic, but worry about the politics in Victoria. Opinion polls show that Daniel Andrews’ Labor government is

unpopular, with opposition claims that Victoria is facing a “crime tsunami”.

Vice President of DWD Victoria, Dr Rodney Syme, has expressed concerns that the opposition may vote against the bill in order to prevent the government receiving any kudos from its successful passage. The fear is that Victorian politics could override genuine consideration of the contents of the bill.

The Victorian panel’s recommended law for VAD

The Victorian Ministerial Advisory Panel made 66 recommendations for the *Voluntary Assisted Dying Bill* in its final report, published on 21 July, 2017.

Eligibility:

A person would need to:

- Be at least 18 years of age
- Be a resident in Victoria
- Have ‘sound decision-making capacity’ in relation to voluntary-assisted dying
- Be diagnosed with an incurable disease, illness or medical condition, that:
 - Is advanced, progressive and will cause death; &
 - Is expected to cause death within weeks or months, but not longer than 12 months; &
 - Is ‘causing suffering that cannot be relieved in a manner that is tolerable to the person’

NB: Mental illness or disability would not exclude a person from access to the scheme, provided all the eligibility criteria are met.

The proposed Victorian scheme is closest to the law in Oregon, which has been operating for two decades. The only notable difference is that in Oregon the person’s life expectancy must be six months or less, based on the Oregon health system’s limited provision of hospice care. Twelve months is recommended for the Victorian law, based on Australia’s other end-of-life laws.

Process:

To initiate the process, the person must firstly make a request to their medical practitioner, who will conduct an assessment. The doctor must ensure the person is properly informed of their diagnosis and prognosis, treatment options, palliative care options, expected outcome of taking the lethal dose and possible risks of the lethal dose.

A second practitioner then conducts an independent assessment. The patient then makes a written declaration of an enduring request, which must be witnessed by two people who are not beneficiaries from the person’s death. The patient makes a third and final request to their medical practitioner. At least one of the doctors assessing the person must be an expert in the applicant’s particular illness and all participating doctors must complete specialist training to be involved in the scheme.

In most cases there should be a minimum of 10 days between first and last request, before the medication is dispensed.

The drug would be self-administered after being dispensed from a compounding chemist, except if the patient is unable to self-administer. In those cases, the doctor would administer the medication, so that people who cannot take the drugs themselves are not be discriminated against. The medication would be kept in special locked boxes, and returned to a doctor if the patient becomes too incapacitated to take it.

The death certificate would record the cause of death as the underlying disease, not that it was an assisted death.

Doctors will be able to conscientiously object to any aspect of the process.

New criminal offences are recommended for:

- * anyone who induces someone to request an assisted death
 - * anyone administering a lethal dose to a person who does not have decision-making capacity.
- A special board would review all cases and be alerted to all requests.

Paul Russell's tactic of quoting himself



Paul Russell (pictured), the Director of anti-VAD lobby group called HOPE, is based in South Australia, but is currently focusing his efforts on Victoria. On 26 July *The Australian* reported: "The statewide poll, conducted by anti-euthanasia lobby HOPE Inc, revealed 49 per cent of respondents did not want the proposed legislation to be rushed, claiming too many unanswered questions remained..... HOPE director Paul Russell said the polling suggested voters were sending the Andrews government a strong message on the issue. 'There is simply no electoral mandate for this legalisation and there is no trust to get this process right,' Mr Russell said. 'Overwhelmingly, Victorians do not want to see this rammed through by the state parliament.' "

On 27 July, Neil Francis responded with a blog on DyingForChoice.com⁽¹⁾ where he observed that, while HOPE's website reports "Polling noted today in the Australian shows a significant level of distrust in our political classes to get the issue of euthanasia and assisted dying right.", there is no other reference to the poll despite the fact that the quoted article describes the poll as being commissioned by HOPE.

A follow-up article in *The Australian* on 3 August stated: "The Sexton survey of 1200 voters in Victoria was conducted last month for the anti-euthanasia group HOPE and shows headline support for the legalisation of voluntary euthanasia at 70 per cent.." It is interesting that this support by the majority of respondents was never mentioned on HOPE's website, nor in the original newspaper article.

Disappointingly, *The Australian* reported the alleged findings without disclosing the survey questions that were asked. It is widely known that poll results can be easily manipulated through use of biased questions. As HOPE have still failed to reveal the questions that were asked, one cannot escape the

impression that biased questioning has been used to manipulate the results. For instance, a question like: "given that palliative care can relieve all suffering, do you think it is a good idea to legalise voluntary assisted dying?" would inevitably lead to misleading outcomes. It is clear that opponents of VAD are willing to use dishonest tactics in a desperate bid to dissuade MPs from supporting the bill.

(1) Neil Francis runs *DyingForChoice.com*, which is a website dedicated to providing excellent opinion pieces and forensic examination of claims made by opponents on VAD. See www.DyingForChoice.com.



Victorian Catholic palliative care providers say they will not cooperate with a VAD law

A recent article in *The Australian* (11 July) reported that St Vincent's Health Australia, Victoria's biggest palliative care provider, will ban its hospitals, health centres and clinicians from any involvement in voluntary assisted dying, if it should be legalised by the Andrews government.



Toby Hall, Chief Executive of St Vincent's Health Australia, said that vulnerable patients would be put at risk by the proposed legislative changes. Hall accused the Victorian government of taking the cheaper option to "give someone a drug and kill them" rather than providing sufficient palliative care for the terminally ill.

Hall was quoted by *The Australian* as saying "We will never provide assisted suicide in our hospitals; our clinicians will not provide it and will not be able to provide it and we will not allow it in our aged-care facilities either,"

(continued overleaf)

In Australia, more than 60% of all palliative care facilities are run by the Catholic Church, and the number of facilities is growing. St Vincent's is Australia's biggest Catholic not-for-profit healthcare provider, owning four hospitals in Melbourne, including the publicly-funded St Vincent's Hospital Melbourne, which has 880 beds, employs 5000 staff and last year treated 54,000 inpatients.

Although the law proposed by the Victorian Ministerial Advisory Panel allows for conscientious objection on the basis of personal religious views, it is intended as a conscience matter for the individual. It is unclear how the new law would stand in the face of Catholic institutions banning hundreds of medical staff in their employment from participating in the VAD scheme.

As these facilities are funded mainly by Australian taxpayers, DWD NSW believes that they have an obligation to comply with patients' wishes, once VAD has been legalised. The Victorian government may have a fight on its hands with these facilities once the law has been passed.

Denton's opinion piece: The religious lobby against assisted dying



Archbishop Anthony Fisher versus Peter Singer in 'The Euthanasia Debate' September 2015

On 17 June, an opinion piece by Andrew Denton was published in *The Saturday Paper*. In typical Denton style, this brilliant commentary exposes the arguments being promoted by the religious lobby, and the disproportionate influence wielded by a powerful Christian minority over our laws.

Below is an extract from the article:

"For those who like to watch reruns of old dramas, there's one happening right now in Victoria. It's playing out in real time and it has a depressingly familiar storyline: how the Christian political lobby,

which represents a small minority of the community, sets out to stop what the clear majority wants. And here's the twist: they will use the processes of representative democracy to get a result that is wholly unrepresentative of the community view. The issue in this case is voluntary assisted dying. Later this year there will be a conscience vote on legislation to be introduced to the Victorian parliament. The vote might be three months away, but already hardcore religious opponents have mobilised.

Vulnerable seats are being targeted. Government MPs on slim margins are being cajoled with the results of a 'survey' purporting to show that Christian voters will punish them at the ballot box should they dare vote for an assisted dying law. Remarkably, the survey has been done anonymously. Even then, it still shows the majority of electors want a law. ...

If it were a revolution, the street banner would be "power to the patient". The shift from paternalism to partnership in the doctor-patient relationship is an important cultural shift under way in medicine. But it is a distinct threat to those who don't like to surrender power, or choice, to others.

Those opponents who come in the name of God will make the case that palliative care can address all suffering at the end of life, even though the palliative care sector itself says it has no answer for the suffering of 5 per cent or more of patients. They will say that in any case it is good for you to suffer because it is through suffering that you will grow and come to know God better.

Of course, that argument doesn't go down well in a secular society, so you may well find that the religious objections come in another guise: in the cloak of compassion. What about the elderly? They'll be coerced to die early, they will say. What about the disabled? They'll be shunted aside and done away with. They will make these claims even though they know they are wrong and dishonest. Shamefully, the religious extremists will leave the genuinely vulnerable – Victorians who are dying – to continue to suffer and to take their own lives ...

The truth is that a voluntary assisted dying law does provide effective safeguards, specifically to protect the vulnerable. And we know they work because this has already happened in the US, where one in six Americans has access to such laws. ...

If you are an MP in a marginal seat and being targeted by the fringe Christian lobby, I urge you to make your decision based on facts rather than the false claims and fear peddled by those who seek to enforce suffering as a virtue. You will do so with the sure knowledge that the vast majority of your electorate will support you....

And if you find your judgement conflicted by your beliefs, consider California governor Jerry Brown, who studied to be a Jesuit priest and consulted other priests before signing his state's death with dignity act into law with these words:

"I do not know what I would do if I were dying in prolonged and excruciating pain. I am certain, however, that it would be a comfort to be able to consider the options afforded by this bill. And I wouldn't deny that right to others."

Acting for the greater good. Isn't that what public service is really about?"

Secularism is growing



The 2016 Australian Census revealed that the largest religion in Australia today is "no religion". More people put that on their census form

than those who nominated themselves as belonging to any particular religion. "No religion" was selected by 30.1% of Australians, an increase of 9% since the last census in 2012. At the same time Catholicism, the most common religion, fell from 25.3% to 22.6%.

The growing secularisation of Australian society is likely to weaken the role of the church, which historically has exerted political influence on matters of social policy, including voluntary assisted dying. In an opinion piece in *The Huffington Post*, Hugh Harris states "For many, marking 'Christian' represents little more than a cultural affiliation. Emphasising the nominal nature of their belief is the fact that the majority of Christians support same sex marriage, and 70% of Catholics and Anglicans support voluntary assisted dying. Of those that support the latter, 84% are non-observant. Since only 8% still attend church regularly, it is high time politicians abandoned the fallacy that religious opposition is a vote-changer."

In a recent article in *The Guardian* (27 June), Dr Rodney Syme, Vice-President of DWD Victoria, stated that the moral authority of Christian churches, especially the Catholic church, is weakening:

"There is a fundamental opposition on moral grounds to assisted dying, but you'll very rarely find the church coming out saying that, because that moral argument does not carry any weight in discussion. They set up a huge number of organisations that don't reveal the fact they are religious or Catholic organisations."

One is Hope. Hope sounds nice, doesn't it? But it's actually a Catholic front."

Denton: assistance to end suffering is a human right

Andrew Denton delivered a speech on 21 July to the Monash University's Castan Centre for Human Rights, arguing that laws that would allow VAD are consistent with the [Victorian] *Charter of Human Rights and Responsibilities Act 2006*.

"We fight to live. It is our very deepest urge. A law to help someone die is written for a very particular, a very small, group of people. They are the very sickest people in our society. The most vulnerable. And there is only one reason why any of them would seek such help — or be given it: because sometimes, despite the best medical care, the only thing that will end suffering is death." Denton said.



He concluded his speech by saying *"It is not about a 'right to die'. It's about a right to ask for help if you are dying and beyond meaningful medical relief. It's about the right to freedom of thought, conscience, religion and belief. It's about the right to protection from torture and cruel, inhuman or degrading treatment. It's about what's right."*

The youtube video of the full speech is available to watch on our website news page (58 mins).

Reports from related groups:

Central Coast group

Thanks to Meg Wallace for giving an informative presentation in May to the Woy Woy Senior Citizens. Members of our group living at Brentwood Retirement Village in Kincumber hosted Judith



Daley, DWD NSW Board member (pictured), as a guest speaker. Brentwood residents subsequently took up a petition in support of voluntary assisted dying (VAD) to present

to their local Member of Parliament (MP). They also decided to form an ongoing discussion group called the Brentwood Village End-of-Life Choices Group. Participants in this group will be encouraged to join DWD NSW, and the Central Coast DWD Committee has offered them a helping hand.

Lynda Voltz MLC, one of five members of the NSW Parliamentary Working Group on the Voluntary Assisted Dying, was the guest speaker at our May quarterly meeting. Lynda encouraged people to write to MPs about the NSW bill, suggesting that we keep our letters short 'if you want them to read it' and preferably handwritten.

Our next meeting is Friday, 18 August, 2017, with Guest Speaker: Peter Cleasby, Chairperson, Central Coast Local Health District Advance Care Planning Committee. Topic: Advance care directives: a local perspective; procedures at Central Coast hospitals



Please note that the excellent documentary *Fade to Black*, will be screened at Hoyts Erina Fair Shopping Centre on Monday August 28 at 2 pm. Tickets are available on-line only (\$20 plus a \$1.65 booking fee) from <https://tickets.demand.film/event/1991>. This is not a DWD NSW event, but if you have questions you can contact Bev Symons on 0413 376 343. For more details see the back cover of this newsletter.

Our final meeting for 2017 will be on Friday, 24 November with Guest Speaker: Coral Levitt, President, NSW Nurses and Midwives Association
Topic: The nurses' union and assisted dying

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

Annie Sobey and Beverley Symons
DWD Central Coast Group
Email: centralcoast@dwdnsw.org.au
Phone: 0413 376 343

Mid-north Coast group



Guest speakers at our May meeting were life partners Susan Murphy and Graeme Atkins (pictured). Their powerful presentation, *'Living and Caring with Alzheimer's and Other Dementias'*, involved both music and talk. Graeme has written many songs about his illness, including one he wrote specifically for DWD and sang for the first time on the day. The couple are sharing their story so that people understand the many challenges faced by people living with dementia, and their carers. Thank you Susan and Graeme for being so brave in sharing such a personal and intimate journey.

In June, Alana Hamilton participated in a panel discussion on voluntary assisted dying, as part of a University of the Third Age (U3A) philosophy course. We thank U3A for this opportunity.

On 11 July, we co-hosted a special public information session in Port Macquarie about the NSW VAD bill. The Parliamentary Working Group on Assisted Dying was represented by the Hon Trevor Khan MLC, who presented an overview of the bill, the background and reasoning behind some of the provisions, and the processes involved. Leslie Williams, the Member for Port Macquarie (pictured below) and her assistant Terry also attended. In her welcome, Leslie



reported that she had received many letters supporting the proposed bill. She encouraged more people to write to her and to make an appointment to see her personally, particularly if they have had a relevant personal experience.

Our next meeting is on 29 August 2017, with guest speaker Ivan McMaster from Orange. His presentation 'Transitioning from Home to Retirement Village/Nursing Home' should be very interesting, especially in the light of recent ABC reports.

The following meeting will be on 28 November and will discuss 'Death doulas and funeral preparations'.

Our quarterly meetings are held from 10am till noon in the Rushcutter Room at Port Panthers Club, 1 Bay St, Port Macquarie (kindly provided at no cost). \$5 entry includes morning tea. Everyone is welcome.



Finally, we have organised a special one-off screening of *Fade to Black* on Wednesday 23 August at 2pm at Majestic Cinemas Port Macquarie.

Please come and support the film. Tickets are available online only (\$21.65 incl. booking fee) from <https://tickets.demand.film/event/1978>. For more details about the film please see the back cover of this newsletter. If you have any questions you can call me on 0432 048 414.

Annie Quadroy

Convenor, DWD Mid-north Coast Group
email: pmq@dwdnsw.org.au
Ph 0432 048 414

Christians Supporting Choice for VE

I have prepared a presentation folder outlining support for VAD from a mainstream perspective, as well as a specifically Christian perspective. A copy has been delivered to each Member of Parliament in the NSW Upper House, and they are progressively being posted or handed to those in the Lower House.

New members supporting our group are very welcome at this critical time. Please help us to publicise the fact that most Christians do support compassionate choice for VAD. Membership is free. Simply let me know your name and address by emailing ian.wood@christiansforve.org.au or writing to my address below.

Ian Wood

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

Queensland Labor votes to support VAD legislation

At the *Queensland Australian Labor Party State Conference* in Townsville on 29 July, the following motion was passed: "Labor will introduce legislation for voluntary assisted dying for adults who are terminally ill, following the model of the Dying with Dignity/Oregon Model, and the Voluntary Assisted Dying legislation in Victoria".

Western Australia hopes to have Inquiry too

In June, a motion to establish a *Western Australian Inquiry into End-of-life Choices* was put on the notice paper by Amber-Jade Sanderson MP. David Templeman MP, who is the government minister responsible for which laws are debated, told media in July that the establishment of this committee of inquiry would be debated in August.

New Zealand bill



On June 8, *The End of Life Choices Bill*, submitted by David Seymour (pictured) back in 2015, was randomly plucked from the members' ballot. If passed, the law would give people over 18, with a terminal illness

or a 'grievous' medical condition, the option to choose assisted dying, if they have the support of two doctors. New Zealand politicians will be given a conscience vote on the bill, which is unlikely to be voted on before the federal election. It appears that it may have the numbers to pass.

Dying with Dignity

New South Wales



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Rather than use this form, you can also choose to make a donation online via our new DWD NSW website - see www.dwdnsw.org.au

**Please post your completed form to DWD NSW PO Box 25 BROADWAY NSW 2007
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MND - Our story

by Les Ware of Port Macquarie, NSW.

Greg was a man of 65 who could do everything - then within 11 months, nothing at all. He was diagnosed with upper and lower body Motor Neurone Disease (MND) on 2 November 2015, and died on 5 June 2016.

Greg was a fine man, held in the greatest esteem by all who knew him, and of course deeply loved by his family and close friends. Greg and I met when he was 18, and we were married for 44 years. I wanted to care for Greg at home and felt able to as I had worked as an aide in nursing homes when I was much younger, and had cared for three terminally ill parents. However, when a person is suffering with MND they need complete attention at all times, not just hourly checks.

The health care professionals were wonderful and were in awe of Greg's mighty courage and spirit. The palliative care team were sometimes amused at the way I improvised to look after Greg in our home. Velcro came in very handy for things like tying poor Greg's arms, legs, and torso to the shower chair or wheel chair. Greg endured the stickiest, thick, almost immovable saliva being vacuumed from the back of his throat throughout the days and nights to prevent him from choking. While Greg could still speak, he was asked if he would want to go to hospital if he developed pneumonia (a common cause of death



for MND patients because they cannot cough). He immediately responded, "No, I don't want to live like that, with tubes out of me." He mumbled the same response one month later, when he had deteriorated further and was asked if he would like

a tube inserted directly into his stomach so that he could eat. I guess we can be grateful that Greg was at least given a couple of choices as to how he was to live his last days. But why then was he not permitted to choose how he would die when the time came? He had no fear of death whatsoever, only of the way this disease would have him go. He knew that the only choice he would be allowed to make would be to starve, or suffocate, or both. Nevertheless, Greg's smile and his acceptance gave us all strength.



Les Ware, with her husband Greg

Once Greg could no longer blink 'one for yes' or 'two for no', that's when I hit a wall. In the last few weeks he was distressed every few minutes but I could no longer find out what the problem was - where was the pain; how to reposition him; was a fly crawling on him; was he thirsty and needed another teaspoon of thickened water? By this time he could no longer smile. But - oh the spirit of a man who hadn't been able to raise a finger for two months. One day when I felt such despair and frustration over not knowing how to soothe him, I fell to my knees, took his hand, and collapsed my head into his lap, sobbing. To my absolute astonishment he slowly lifted my hand to his lips - both of us in disbelief! For as long as I live I will never know how he did that - except through love...the most powerful force on earth.

Not only was he suffering pain, I knew he was suffering greatly knowing that I was utterly exhausted, had a stomach hernia and wrist ganglion from lifting him, and he couldn't even hold me or tell me he loved me. It was heart-breaking for us both.

My husband, as did our parents, fought to stay alive while they had ANY quality of life. It should be nobody's choice but our own to say what we can bear and how far we can go before we've had enough. Greg's body had been ready to die for quite some time, but not the way that our leaders would have him pass. Had I the means and permission, I certainly knew his wishes and had the love to empower me to lay my soulmate to rest. If only our country's leaders had a little of that love and compassion in their hearts. Parliamentarians fear losing their seat. Unnecessary suffering makes absolutely no sense whatsoever. Who knows what could drive anyone to vote against being humane?

Fade to Black - the film



Fade to Black is a feature-length documentary that follows the travails of Peter Short, who mounted a personal campaign to legalise voluntary assisted dying in the lead-up to his death in December 2014. Raising \$160,000, it is the most successful crowdfunded Australian documentary. It is premiering across Australia throughout August and September.



Peter Short with filmmaker Jeremy Ervine in December 2014.

Fade to Black is centred around the personal story of Peter Short, the charismatic CEO of a major Australian company. He is diagnosed with terminal oesophageal cancer on his 57th birthday and learns that he has only months to live. After hearing about Dr Rodney Syme, who has admitted that he has helped many terminally ill people to end their lives, Peter was inspired to meet him.

Peter was not only comforted by the idea of having control over the end of his life, but felt it was his right to choose it. After meeting with Dr Syme, Peter started raising awareness about the law getting in the way of his freedom to choose, and joined forces with DWD to campaign for voluntary assisted dying.

Filmmaker and Producer, Jeremy Ervine, shot more than one hundred hours of footage and interviewed dozens of people for this movie. *Fade to Black* provides a history and background to the issue of assisted dying, including the passing and subsequent undoing of legislation in the Northern Territory, and the laws that exist in other countries.

The film features interviews with key players in the debate, including Dr Rodney Syme, Andrew Denton and Dr Philip Nitschke, as well as politicians for change, Dr Richard Di Natale and Fiona Patten. Whilst presenting a balanced view of the issue (including footage of arguments mounted by the Christian opposition), ultimately the pro-choice view prevails. With law reform now on the agenda, we hope that *Fade to Black* will be a powerful force for change.

The premier screenings in Sydney on 3 August were followed by excellent panel discussions hosted by ABC radio personality, Tony Delroy. Peter's widow, Elizabeth Short, was on the panel and did a number of radio and television interviews in the lead-up to the film launch. She is encouraging people to get inspired by the film and then write to, call or visit politicians. Elizabeth predicts that only complacency will destroy this critical opportunity for success.

One-off screenings of *Fade to Black* are also planned at Port Macquarie (23 Aug); Murwillumbah (24 Aug); Erina (28 Aug); Newcastle (11 Sep); Mount Victoria, Hurstville & Sawtell (12 Sep); Glendale & Armidale (13 Sep); Wagga (14 Sep) and Campbelltown & Ballina (18 Sep). For more details and to buy tickets see the website www.fadetoblackmovie.com



Linda Scott, Elizabeth Short and Shayne Higson at Sydney Premier.

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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