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Dying with Dignity

New South Wales



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PO Box 25 Broadway NSW 2007 | Phone 02 9212 4782 | Email dwd@dwdnsw.org.au

President's message



Lots of interesting things have been happening over the last few months. The highlight was undoubtedly Andrew Denton's address to the *National Press Club* (NPC) on 10 August. To say that Denton's speech was powerful is an understatement. It was the most cogent and compelling case for a change in the law that I have witnessed. Even NPC Director, Mark Kenny, who hosted the event, remarked "*we've scarcely heard a more powerful address at the Press Club*", a comment echoed by other journalists present. (The video and full transcript of Denton's address is available on the DWD NSW website.)

At the NPC address, Denton launched the book, "The Damage Done", which is a compilation of testimonials that describe the suffering experienced by individuals who are impacted by current laws. It provides a powerful repudiation to opponents who claim that "*no one needs to suffer... we have drugs for that*", and is a great resource to pass on to politicians. Denton also launched a new organisation, "Go Gentle Australia" (GGA), which aims to promote legislative change with the use of social media, online information and key articles, creation of videos and other forms of promotion. (See pages 6 - 7).

In Victoria, the Parliamentary Inquiry recently presented their findings, which included the recommendation that voluntary assisted dying (VAD) should be legalised. Thousands of hours have gone into conducting the investigation, including processing of detailed submissions, public hearings, data collection and overseas travel to investigate how the laws operate in countries where VAD is legal. Substantial work and taxpayer dollars have gone into this process. It is now incumbent on Victorian politicians to implement its recommendations. If these findings are ignored, it will make a farce of the whole process. We will be very interested to see if Premier Daniel Andrews is prepared to lead on this issue (See page 4).

The *NSW Parliamentary Working Group on Assisted Dying* is in the process of finalising the bill they plan to present to the NSW Upper House, hopefully some time this year. Once the dates have been set, we will be urging our members to contact Upper House MPs via personal visits, letters and phone calls, to let them know why this issue matters. Communication from constituents has a significant influence on the way that some MPs respond to conscience votes, particularly those who are "fence sitters", so making our views known is very important (See pages 5-6 for more details).

The federal election provided a good opportunity for us to survey the federal political parties, and ask for their stance on VAD. Our thanks to those of you who approached politicians and got back to us. The views of federal politicians have become relevant because of the Greens' plan to launch their "Dying with Dignity (Medical Services) Bill" in the Senate some time during the term of the current parliament.

A significant development in recent months has been our decision to update the DWD NSW Constitution. This decision was based on legal advice, and the reasons for the changes are explained on the next page. Although the DWD NSW constitution is not a 'sexy' topic, I hope that members will be prepared to come along to our extraordinary general meeting on 1 October, and vote on the changes. The proposed new Constitution is on our website, or available as a hard copy upon request.

Finally, my special thanks to writer, broadcaster, historian and presenter-extraordinaire, Professor Ross Fitzgerald, for his fabulous presentation at our AGM. Ross, who stood for the *Australian Sex Party* in the recent federal election, is a passionate supporter of our cause. His speech, highlighting the influence of religious groups in political processes, was compelling and entertaining. (For those who missed it, the transcript is available on our website).

There are lots of other issues also discussed in this newsletter. I wish you all happy reading!

Sarah Edelman

President, DWD NSW

Changes to our DWD NSW constitution

After much consultation, the Dying with Dignity NSW committee has concluded that we need to update our constitution. The current constitution was written in 1983, and established us as a “public company limited by guarantee”. It was prepared in accordance with the laws that were in place at that time. Since then, there have been significant changes to the laws applicable to companies, and to the regulatory regime which governs them. The establishment of the *Australian Charities and Not for Profits Commission* (ACNC) in 2012 has changed the way in which Australian charities and not-for-profit entities are regulated.

We have been very fortunate to have the assistance of one of our life members, lawyer, Penny Hackett, who has been providing free advice on how we can update our constitution. With input from us, Penny has prepared a replacement constitution, based on the template recommended by the ACNC for companies limited by guarantee. This is regarded as a “best practice” document, and reflects the latest corporate governance practices and up-to-date legal provisions.

There are some significant advantages to making these changes. One is that it will allow Dying with Dignity NSW to be registered as a charity with the ACNC. Once this is achieved, we will be able to apply for certain tax exemptions under the Tax Act, including deductible gift recipient (DRG) status. If this application is successful, it would mean that donations to our organisation would then be tax deductible.

The current and the proposed constitutions are available on our website for inspection (see link on our homepage). If you do not have access to a computer, you can phone 02 9212 4782, and we can post you a printed copy. In order to make these changes, we will be holding an extraordinary general meeting to vote on the adoption of the new constitution. All financial members of DWD NSW will be sent a formal notice of the meeting and a proxy form with all the relevant details about the meeting.

The resolution will require at least 75% of votes in order to pass. All financial members of DWD NSW are invited to come along and vote. If you are unable to attend the meeting but would like to exercise your right to vote, then complete the proxy form and email or mail it in to us.

The meeting is on **Saturday 1 October at 1.00 pm at the Sydney Mechanics School of Arts Theatre, 280 Pitt St, Sydney**. The only agenda item at the meeting is the approval of the new constitution. For the proposed constitution to be ratified, there is a minimum number of members required to physically attend, so if you are planning to come along please email us at dwd@dwdnsw.org.au or leave a message on 9212 4782.

Victorian Parliamentary Committee's Report

The Victorian *Legal and Social Issues Committee* was set up in May 2015, to consider questions related to end-of-life matters. It was composed of three Liberal MPs, three Labor MPs, one Green, and the leader of the Australian Sex Party, Fiona Patten.



Over the last year, the committee held 17 public hearings, and received more than 1,000 submissions. It heard from doctors, nurses, palliative and aged care specialists, legal experts, ethicists, academics, religious bodies, community organisations and from the terminally ill and their families. Members of the committee also travelled overseas to study the experience of countries where voluntary assisted dying (VAD) is legal.

On 15 June, 2016, the committee tabled its final report, which included recommendations on palliative care, advance care planning and assisted dying. One of its key recommendations was the enacting of legislation to make VAD available for people who are terminally ill. Although the committee had a Victorian-focus, the report has implications for all states of Australia.

The findings were greeted with enthusiasm by many, including *The Age* newspaper, which published a highly supportive editorial and an excellent summary of the current situation. The first few paragraphs of the editorial read:

“We congratulate the Victorian cross-party parliamentary committee that has recommended a law to enshrine the right of terminally ill people to physician-assisted death, also referred to as voluntary euthanasia. After a 10-month comprehensive inquiry, the committee has opened the way for Victoria to become the first state to protect the doctors of terminally ill patients who are suffering terribly and wish to choose the manner and timing of their death. Life is inestimably precious and should be protected – but not at all costs.”

We urge Premier Daniel Andrews and Opposition Leader Matthew Guy to give their parliamentarians a conscience vote on any bill that is presented. The government has six months to respond. Mr Guy has declared he does not support changing the law. Mr Andrews is yet to make up his mind.

The arguments for allowing terminally ill patients to die in a manner and at a time of their choosing are compelling and compassionate. Were there a free vote, the law would be likely to be passed; community support for such a change has been mounting, to the point that as many as eight in 10 people now believe it is the right thing to do. This momentum is reflected across the nation.

The parliaments of South Australia and Tasmania are considering legislating what we believe is a fundamental human right. Greens leader Dr Richard Di Natale has introduced a similar bill into the federal parliament. It is not clear when that might come to a vote, but then-prime-minister Tony Abbott promised the Coalition members would have a free vote on it.

It is noteworthy that a cross-party Senate inquiry a few years ago, which included Senator Di Natale, made the same recommendation the Victorian one has just handed down”.

VAD supporters on NSW Senate crossbench

Counting is finally complete for the July 2 federal election. We have seen some significant changes in terms of representation from minor parties in the Senate. With the prospect of a federal voluntary assisted dying (VAD) bill in the current parliamentary term, it is interesting to see a substantial number of the new crossbench Senators declaring their support for legislative change.

Supporters of VAD include Jackie Lambie, Derryn Hinch, Pauline Hanson's four One Nation senators, Liberal Democrat, David Leyonhjelm, and all the Greens Senators. Some, like Derryn Hinch, have a very personal interest in this issue. (Hinch was diagnosed with liver cancer in 2007).

The support of these crossbenchers could be pivotal in getting a federal VAD bill over the line in the Senate.

Anthony Albanese

Unlike some of the minor party candidates, MPs in the major parties have been far more timid in coming forward with their view. Anthony Albanese, Opposition front bencher and Member for Grayndler, is one of two Federal MPs who came along to the Press Club to hear Denton's address. (The other was Greens Senator, Richard di Natale).



Bob Hawke and Anthony Albanese in February 2016.

Albanese had made his views known publicly 20 years ago during the parliamentary debate about the "Andrew's Bill", which banned the Australian territories from legislating on the issue. Albanese recently reiterated on *Sky News*, "I'm a supporter of voluntary euthanasia". He added that a bill on this issue should be subject to a conscience vote, and any legal regime should have proper safeguards to ensure the interests of dying people were protected.

Bob Hawke

It was good to see former Australian Prime Minister, Bob Hawke, come out publicly in support of assisted dying laws. His comments that it is "absurd that euthanasia is not legal in this country" and that opposition "doesn't meet any requirements of morality and good sense" were widely reported in various media outlets.

"I am more than happy for my name to be associated with a clear statement of belief that the time has come where we in Australia should have clear legislation on our books that makes euthanasia legal" he said.

Commenting on politicians' reluctance to reflect public standards on this issue, Hawke said, "Well, politicians are by and large not the bravest of creatures... They have a preeminent interest in retaining the seat they hold in the parliament."

Greens VAD Bill to run during this federal term

Greens leader Richard Di Natale has recently reaffirmed their intention to submit a bill in the federal parliament to legalise VAD. 'We are calling on both the opposition and the government to support a free vote so that Australians right around the country, if they have a terminal illness, will have the option in their final days of knowing they won't die a death that entails so much suffering'.

Former Greens leader, Bob Brown, backed Senator Di Natale's call: "This is about human compassion and kindness, and the right of people to make up their own minds on what may be the most important decision of their lives" he said.

While it might be wishful thinking to imagine that the majority of MPs will support the bill, it is remotely possible that a genuine conscience vote could get it over the line in the Senate. This is because a substantial number of the crossbenchers have declared themselves to be supporters of VAD. If a genuine conscience vote is allowed, it is possible that many Labor senators and some on the Conservative side of politics will also vote in favour of the bill.



Dr Sarah Edelman, Dr Richard Di Natale and Elizabeth Short (wife of the late Peter Short, Victorian VAD campaigner) at Andrew Denton's *National Press Club* Address.

NSW Working Group

The NSW Parliamentary Working Group on Assisted Dying (PWGAD) have drafted the "Voluntary Assisted Dying Bill (2016)", and in the last few months they have been undertaking consultations with key stakeholder organisations. Representatives of our DWD NSW Committee and Ian Wood from *Christians Supporting Choice for Voluntary Euthanasia* met

with representatives of PWGAD in early August, and provided detailed recommended amendments to the draft bill. The DWD NSW group in Port Macquarie and Central Coast also provided some written feedback to them. The PWGAD also met with and received submissions from other organisations, including *Doctors for Voluntary Euthanasia Choice*, *Go Gentle Australia*, *ACON*, *The NSW Bar Association*, *The Law Society of NSW*, and *The NSW Council for Civil Liberties*.



The Hon Trevor Khan MLC, Chairman of the NSW Parliamentary Working Group on Assisted Dying, speaking to the DWD Port Macquarie Group on 7 June about the planned NSW bill.

The various recommended amendments are now being considered by PWGAD and parliamentary counsel, before being incorporated into a final bill. It is expected that the bill will be introduced into the NSW Legislative Council during the Spring session of Parliament. Being proposed by a cross-party working group (with members from the Nationals, Liberal and Labor parties and the Greens), increases the chances of a genuine conscience vote. Nevertheless, we expect opponents to mount a massive scare campaign when the bill is debated. At this time, DWD NSW will contact our supporters to encourage you to lobby NSW MPs.

Andrew Denton: National Press Club address

On Wednesday 10 August, Andrew Denton addressed the *National Press Club* (NPC) on the subject: ***'The Damage Done. The price our community pays without a law for assisted dying'***. In his address, Denton highlighted the way that Australian politicians are being too easily persuaded by vocal, mainly Christian, lobby groups. These groups are engaging in a deliberate strategy of denialism, and propagation of myths. *"Myths that have been planted in the minds of many as truth, because at face value, they sound plausible. By failing to properly examine the claim that 'no safeguard can be devised to protect the vulnerable', our politicians have failed, instead, to protect the people they represent."*

Denton cited the recent Victorian Parliamentary Inquiry which heard evidence from the Victorian State Coroner, John Olle, about how elderly Victorians - one a week - are killing themselves in horrific ways.

The Inquiry also found assisted dying was already happening in Australia but *"without regulation, without support, without transparency or accountability, and sometimes without consent."*

"The favourite dog whistle used by opponents of assisted dying, [is] the insinuation the most vulnerable in our society ... would be coerced to die under these laws because they have become a burden" he said. "There is no credible evidence to support this overseas. Rather, there's a mountain of widely accepted, publicly available, peer-reviewed evidence to disprove it."

The final section of his NPC speech reads:

"We are a compassionate society. But we have not been aware of the scale of the damage. That's why I've come to light a fire. A fire for all the people in this book and also for those whose stories we do not yet know. I invite them to come forward and make it bigger.

I invite those doctors and nurses who've seen this suffering, and know it to be wrong, to add to this fire and light it in their hospitals and their communities. I invite all state coroners to build it higher by joining Coroner Olle in casting light on how our elderly are dying. Let us make a fire so big, no politician can ever again ignore it.

To those whose beliefs instruct you that only God can decide how a human being should die, I urge you, step aside. May your beliefs sustain you and those you love, but do not impose them on the rest of us.

To those doctors for whom 'doing no harm' means that you cannot, in conscience, participate, I urge you, too, to step aside. Do not stand in the way of other doctors who, in equally good conscience, see leaving a patient to suffer when they are beyond meaningful medical help as doing more harm. Step aside and let no one question your right to do so. The very core of these laws is that they are voluntary. For doctors and nurses as much as patients.

And to those doctors who are sitting on the fence because you think it's all being taken care of, or

because you don't understand how these laws work, educate yourselves. The safeguards written into these laws protect, not just your patients, but also you.

To the politicians of South Australia, who, for the 14th time, have a Bill before them – and to those of Victoria, Tasmania and NSW, who can expect new Bills within the year – I urge you: Do your duty. Debate these laws properly. Understand what they are. Look at the evidence from overseas about how these safeguards work. And read this book. Enough copies have been printed for every State and Federal politician in Australia.

Should you continue to stand in the way of a law for assisted dying, let it be in full knowledge of the suffering taking place in our community because of that refusal. Write this law. And right this wrong.”



Denton's Press Club speech was widely reported, and generated a series of follow up interviews, including with ABC *Lateline*, *The Bolt Report* (*Sky News*) and several radio interviews. Much of the follow up reporting focused on Denton highlighting the role of religious groups opposing law reform, in what he called “*the theocracy hidden inside our democracy*”.

The video and full transcript of Denton's address is available on our DWD website.

Go Gentle Australia

At the Press Club address, Denton launched his new organisation “Go Gentle Australia” (named after the poem by Dylan Thomas: “Do Not Go Gentle into that Good Night”). It 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.

Go Gentle Australia (GGA) also aims to educate Australians about choices available to them at the end of their life, and to encourage a better conversation around dying. This includes discussion among doctors and nurses, as well as patients, their families and carers. More information is on the GGA website: www.gogentleaustralia.org.au.

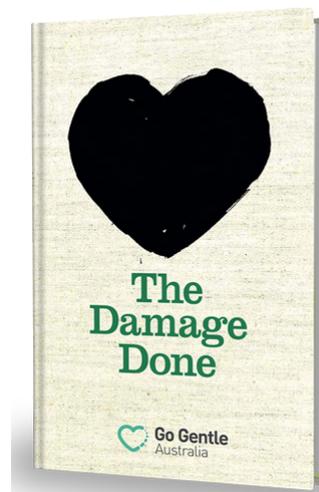
The GGA website is linked to Facebook, Twitter and YouTube, and is operated by a social media manager. The organisation has recently published some high impact video interviews with nurses and doctors, and these are available on the website for public use and promotion.

GGA is receiving valuable campaign communication advice from Tanya Jones, who has many years' experience in political campaigning (including the ‘Kevin07’ campaign). The organisation hopes to work in strong partnership with the existing Dying with Dignity organisations in each state.

“The Damage Done”

At the *National Press Club* address, Denton launched the new book, “The Damage Done”, which contains 73 personal stories of Australians who suffered (or are still suffering) as a result of our current inadequate laws. Compiled by GGA, it contains the testimonies of sons, daughters, husbands, wives, partners, and friends, as well as the dying themselves. Their accounts detail trauma and suffering on a staggering scale.

The book includes contributions from a number of DWD NSW members and we appreciate their willingness to share their story.



GGA will be providing printed copies of the “The Damage Done” to journalists and politicians, including those in the South Australian Parliament, who face a parliamentary debate soon.

It can be downloaded as a free ebook from the GGA website or the DWD NSW website home page.

AMA debate

Over the last few months, *The Australian Medical Association* (AMA) has been reviewing its policy on voluntary assisted dying (VAD). As part of this review it conducted an online survey of its members, as well as a forum on the topic, at its national conference on 27 May 2016. There has been some suggestion that the AMA could shift their official stance on VAD from opposed to “neutral”. In countries where VAD has been legalised, the support of key medical bodies has been critical. At the very least, dropping its policy of opposing VAD would be a significant step forward.

The AMA forum on assisted dying was moderated by Tony Jones of the ABC’s Q&A program, and included contributions from a panel of four medical practitioners and a medico-legal. Familiar arguments were promoted by vocal opponent of VAD, Dr Karen Hitchcock: *“Oregon-style laws were unnecessary and could actually be harmful, by making the elderly and disabled feel pressured into seeking assisted dying, such as because of the fear of being a burden to their relatives.”*

VAD supporter, Emeritus Professor Bob Douglas, stated *“From the perspective of a patient, my concern is that when I get to the point of incurable illness and inevitable death, I don’t want to put all my relatives through the pain and suffering of an unnecessarily elongated process”*. He argued that laws similar to those enacted in the US state of Oregon would give a lot of people comfort.

The findings of an AMA member survey, which apparently received 4000 responses, have not been released. AMA President, Dr Gannon, said the findings would be used to help inform the AMA Federal Council decision, when it meets in August. We keenly await this decision.

Go Gentle Australia has just created some short videos focused on the position of health professionals on the issue of VAD. In the video



AMA Conference Panel on VAD: (L to R) Associate Professor and Geriatrician Mark Yates, Emeritus Professor Bob Douglas, medico-legal expert, Georgie Haysom, Moderator Tony Jones, Dr Karen Hitchcock and Professor of Ethics Malcolm Parker.

titled “The AMA does not represent me”, doctors speak out and remind the viewer that AMA membership includes only 30% of doctors in Australia. See the GGA Facebook or website www.gogentleaustralia.org.au/doctors.

In its report on the session, the AMA website currently reads: *“While opinions clearly diverged on whether or not doctors should be involved in euthanasia and/or physician assisted suicide, there appeared to be consensus on at least one major issue - the medical profession can do better to support patients and their family members at the end of life.”*

It is worth highlighting here that whenever doctors or politicians respond to questions about legalising VAD by talking about the need to provide better services, better advance care planning, more conversations about death ... we should be wary. This is a tactic frequently used for sidestepping the issue. Whilst nobody disputes the need for better palliative care and support for patients across Australia, this is a separate issue to legalising assisted dying. The provision of excellent medical care and palliative care services does not negate the need for the option of an assisted death, when one is hopelessly ill and suffering.

A **civilised** society wouldn't choose between granting people the **right** to a **humane assisted death** and more funding for **better palliative care**

A **civilised** society would prioritise **both!**

Voluntary Euthanasia Party (VEP) update

In the recent federal election, the VEP contested Senate seats in NSW, South Australia and Victoria. The Senate election results have now been finalised, and I can report that in NSW, the VEP received 15,198 primary votes, or 0.34% of the formal votes. This was the best result out of the three contested jurisdictions.

I have no doubt that this was largely due to the dedicated volunteers who letterboxed and/or handed out 'How To Vote' flyers on election day. I would particularly like to thank Sandi Steep, our Party Secretary, and Dr Janise Farrell, the second candidate on the VEP ticket, who both worked very hard in the lead-up to the election, as well as all the volunteers who helped with our campaign.

Although the result was better than the last federal election, we were still well short of achieving a Senate seat. The VEP NSW finished 22nd out of the 41 groups that contested the NSW Senate seats, and as the lead candidate, I was 30th out of 151 candidates.

'Personality' parties were the big winners in the 2016 Senate, but at least the "parties" set up by Jackie Lambie, Pauline Hanson and Derryn Hinch, all support assisted dying law reform, as does Senator David Leyonhjelm from the Liberal Democrats, who won the last seat in NSW.



Andrew Denton and Shayne Higson at the "Di Gribble Argument" in October 2015. This event launched Denton's VAD campaign.

I also have some news of a more personal nature to report. A few months ago, high-profile campaigner, Andrew Denton, asked me to join him in his efforts to bring about law reform for voluntary assisted dying. At that time I was committed to continue in my VEP roles until after the Federal Election. Immediately after the Election, I started working with Andrew and his producer, Bronwen Reid, on the creation of 'The Damage Done'. It was quite an experience to read the heart-breaking personal stories of suffering provided by many of you. I am now working full time with Denton's new organisation called Go Gentle Australia (GGA).

The other organisation that had previously wanted me to join their committee is Dying With Dignity NSW. Accepting this role would not have been possible if I stayed as Convenor of the VEP (NSW) as DWD NSW is not aligned with any particular political party. By resigning from my position as Convenor and stepping down from the VEP (NSW) committee, I have been able to join the DWD NSW committee. I feel that I can make a greater contribution over the next three years, at least until the next state or federal election, by taking on these new roles.

Judith Daley, has also resigned from the VEP Committee due to ill health, so I would like to thank Judith for her contribution over the past two years. I know I am leaving the VEP (NSW) in good hands and am pleased to announce that Pam Burling will replace me as the Convenor of the State Foundation Executive Committee. There are also four new enthusiastic faces on the NSW Committee, joining longstanding campaigner, Dr David Leaf, Treasurer, Brian Owes and Secretary, Sandi Steep.

I look forward to an ongoing relationship with you all in my new roles at GGA and DWD NSW.

Shayne Higson
Former VEP(NSW) State Convenor
Committee Member DWD NSW



Dr Janise Farrell, second candidate on the VEP NSW Senate ticket, working at the Leichardt Town Hall polling booth on election day.

NSW Nurses & Midwives Assoc. Annual Conference

Nurses are one of the professional groups most supportive of legislative change, perhaps because they have close contact with people who are dying, and are frequent witnesses to pointlessly drawn out deaths. In July, over 700 nurses, midwives, members and guests from across NSW gathered at *Rosehill Gardens Grand Pavilion* to attend the *NSW Nurses & Midwives Association Annual Conference*. Dying with Dignity NSW held a stall at the conference for the third year in a row, providing information and DWD NSW brochures to participants, as well as recruiting new members.



The 2016 conference was special for the representatives of DWD NSW, as Andrew Denton was a keynote speaker and talked about why assisted dying should be a legal option at end of life. *"It still amazes me that we live in a society where it is legally and ethically acceptable for a dying patient to choose a slow, psychologically painful death by dehydration and starvation, but legally and ethically unacceptable for that same dying patient to choose a death that is quick and painless"* he said. The full audio recording of his speech is available on both our website and that of the NSWNMA.

DWD NSW Port Macquarie group

Our last meeting was on 7 June, with 58 in attendance. The Hon. Trevor Khan MLC, spoke in his capacity as Chairman of the *NSW Parliamentary Working Group on Assisted Dying*, about their current work on a draft assisted dying bill for NSW in 2016. He spoke with refreshing openness about the group's reasoning behind inclusion or exclusion of the various components of the legislation. Since then, our group has had the opportunity to comment on the draft of the NSW bill.

Ms Shayne Higson also addressed the meeting in her capacity as Lead Senate candidate for the Voluntary Euthanasia Party at the 2016 Federal Election. She told her personal story and her campaign efforts to date.

On Friday July 1 the Port Macquarie Mayor, Peter Besseling, pictured here, held a media event on *The Glasshouse Podium* to announce that the box



office was now selling tickets for our special DWD event: **"An Evening with Andrew Denton"**. It will be held at *The Glasshouse Theatre*, Port Macquarie, on Friday 22 November 2016 at 7.30 pm.

DWD PMQ have received great assistance from the staff of *The Glasshouse* in our preparations. Denton's accommodation at *The Observatory* has been donated by Drew Johnston of Newcastle. Initial tickets sales are going well, with over 150 seats sold 3 months out. *The Glasshouse Theatre* can fit up to 600 people, so buy your tickets now.

Tickets are all \$45 and can be purchased directly from *The Glasshouse* box office (Corner of Clarence and Hay Streets Port Macquarie) or by phone 02 6581 8888 or their website www.glasshouse.org.au/Whats-On/An-evening-with-Andrew-Denton-2016

Our last quarterly meeting for the year is on Tuesday 6 September. Our Speaker is Adam Easter, a prominent local financial advisor, who will inform us about the latest changes to Commonwealth benefits and legislation.

Our quarterly meetings are always held at 10 am till noon at "The Pier", *Port Macquarie Panthers Club*, 1 Bay St, Port Macquarie, which is kindly provided free to us for our meetings. Everyone is most welcome.

Bruce Gibbs

Port Macquarie Group Leadership Team

email: dwdpmq@gmail.com

phone 0432 048 414 (Annie Quadroy Co-ordinator)

DWD NSW Central Coast group

At our May meeting, Dr Sarah Edelman gave a update on the campaign for VAD in NSW and nationally. Afterwards we watched an ABC report on Dr Rodney Syme, and several short videos of people with terminal illness pleading for choice. These made a powerful impression on audience members.

At our August meeting, we held a members' forum on "Why legal voluntary assisted dying is important to me". Speakers were Dr Tony Adams AM, Annie Sobey (CC Committee) and Meg Wallace, PhD (read in her absence). The meeting was then open to the floor to tell their own personal experiences, followed by questions. This type of meeting was a first for the Central Coast group and went very well.

In July, the *NSW Parliamentary Working Group on Assisted Dying* invited us to submit comments on the Consultation Draft of the NSW draft non-governmental bill "Voluntary Assisted Dying Bill 2016", which we were very happy to do.

At our last meeting for the year, on Friday 25 November 10 am to 12 pm, we will have DWD NSW Committee member, Judith Daley, speak about her motivation for becoming involved with DWD NSW and VEP. We will also view a short film and have some seasonal treats. All our meetings are held in Meeting Room No. 3, The Hive, Erina Fair (opposite the Erina Library desk). Everyone is most welcome.

Joy Shannon

Central Coast Group Secretary
email: centralcoast@dwdnsw.org.au
phone 0413 376 343 (Bev Symons Co-ordinator)

Christians Supporting Choice for Voluntary Euthanasia (Ch4VE)

I was very pleased to represent our group at Andrew Denton's address to the *National Press Club* on 10 August. We are all thrilled and re-motivated by Denton and his podcasts, speeches, radio broadcasts and the confronting new book "The Damage Done" – which includes testimonies from members of our group.

I was pleased to be able to represent Ch4VE at a meeting with the *NSW Parliamentary Working Group* to provide feedback on their draft VAD bill.

As our group started in South Australia, we have a big supporter base there and our members will be encouraged to maintain contact with their local MPs when debate resumes on the SA Parliament in September (more details below).

New members to our group are very welcome, and I thank those who have joined us in recent weeks. Membership is free. Join via our website www.christiansforve.org.au or write to advise me of your name and address by email or post.

Ian Wood

National Co-ordinator, Christians for VE Choice
email: ian.wood@christiansforve.org.au
Villa 1/4 Wills Place, Mittagong NSW 2575.

South Australian news

A bill to legalise voluntary assisted dying (VAD) is due to be debated in the South Australian (SA) Parliament on 29 September. The bill was introduced to the SA House of Assembly in February, by Steph Key (Labor), and seconded by (Liberal) Leader of the Opposition, Dr Duncan McFetridge. This will be the 14th occasion on which a VAD bill has been presented to the SA Parliament. Under the new bill, to qualify for VAD, the person must have a diagnosis of a medical condition, and be experiencing "unbearable and hopeless suffering". However it need not be terminal, as was required in previous legislative attempts.

During initial debate in June this year, nine speakers spoke strongly in favour of the bill, including the Premier and the Opposition leader.



Premier Jay Wetherall, pictured, revealed that his grandfather had "begged" a doctor to end his life. He argued that MPs must "find a way" to pass laws which give people "genuine choice" about what happens at the end of their life. The SA Premier had previously met with Andrew Denton, who he said had made "many compelling arguments".

It is very encouraging to see that both the Premier and Opposition leader support the SA bill. This will help to ensure that members of the SA parliament have a genuine conscience vote, and therefore, increase the chances of the bill being successful.

NB: If your annual membership is due for renewal you will be posted a renewal notice or sent an email asking you to renew. Please do not assume that getting this form in the newsletter means you have to renew now.



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Dying with Dignity NSW

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International News

Canada's law comes into effect

After weeks of debate, Canadian lawmakers have passed legislation to allow voluntary assisted dying (VAD), under strict criteria. Last year the Canadian Supreme Court had ruled that the Parliament must legalise assisted dying, but did not specify the provisions or safeguards that should be included. Canada's Prime Minister, Justin Trudeau, backed the legislation, which came into effect in August.

The new law limits assisted dying to the incurably ill, and mandates a 15-day waiting period.

Other eligibility criteria include:

- Residence in Canada and eligible for government-funded health care (to prevent suicide tourism)
- Mental competence, and at least 18 years of age
- Proof of suffering a serious and incurable disease, illness or disability

- Evidence of being in an 'advanced state of irreversible decline', with enduring and intolerable suffering.

As a safeguard, the law also requires two independent witnesses be present when the request for a doctor-assisted death occurs, and does not compel doctors to assist.

One hundred and sixty-six assisted deaths in Quebec

In Canada's French province of Quebec, VAD was legalised in December 2015. The Quebec law, which is narrower than the recently passed Canadian federal law, requires that applicants "be at the end of life".

Since December, 253 Quebec patients have requested the procedure, and 166 have received it. Dr George L'Espérance, President of Quebec's leading right-to-die group, said the high number of requests could be due to a back-log of patients waiting for the law to come into effect.

United Kingdom



One of Britain's most famous actors, Lord Brian Rix, died on 20 August, aged 92, in a retirement home for actors in north London, where he had been for a year and a half. Lord Rix, pictured, only recently revealed that he was dying, and sent an emotive letter to the Speaker of the House of Lords, pleading for VAD to be legalised. He urged parliament to act "*as soon as possible*" to enable people in his situation to be assisted to die.

He stated "*My position has changed. As a dying man, who has been dying now for several weeks, I am only too conscious that the laws of this country make it impossible for people like me to be helped on their way, even though the family is supportive of this position and everything that needs to be done has been dealt with..... all I want is to be allowed to slip into a sleep, peacefully, legally and without any threat to the medical or nursing profession.*"

Ironically, Lord Rix voted against the *Assisted Dying Bill* when it came before the House of Lords in 2006, for fear that people with learning disabilities might be vulnerable under the law.

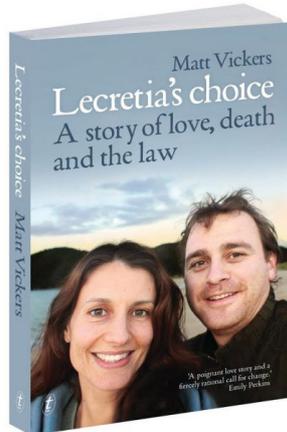
Meanwhile, Sir Richard Thompson, former President of the *Royal College of Physicians*, and the Queen's private doctor for 21 years, is one of a growing number of eminent British doctors who want assisted dying to be made legal. Thompson stated that doctors have a duty to help their patients die, and it should be a part of their jobs. This is in contrast to the stance taken by the *British Medical Association*, which recently rejected a call to take a neutral stance on VAD.

New Zealand

The voluntary assisted dying (VAD) debate is back on New Zealand's political agenda, as support mounts for a Parliamentary Inquiry. A petition calling for an Inquiry received 21,000 submissions from across NZ, with more than 1,800 impassioned submitters requesting to appear in person before Parliament's Health Select Committee.

In previous years, NZ's parliament voted down members' bills seeking to legalise VAD. David Seymour, leader of New Zealand's ACT party, has confirmed that he is drafting a new member's bill, calling for renewed debate on VAD. He believes New Zealanders' stance on this issue has changed in recent years, with polls suggesting most are now in favour of choice.

The death last year of Wellington lawyer, Lecretia Seales, who lost her bid for an assisted death, generated high levels of public support and engagement in the debate.



Recent promotional events across NZ to launch a book called "Lecretia's Choice", written by her husband, Matt Vickers, has also kept the issue in the mind of many New Zealanders. (The book will be available in NZ and Australia from *Text Publishers* on 29 August 2016).

California

Last year the Californian parliament passed a law to allow voluntary assisted dying (VAD) for individuals with terminal illness, and in June this year, the law was put into effect. This means that 16% percent of the US population now has access to VAD, up from 4% prior to the Californian legislation.

Many Californian hospitals have not yet released policies for dealing with the law, although several Catholic facilities have stated that they will not cooperate. (The law states that no doctor, health system or pharmacy will be forced to comply with a patient's request).

Religious opponents have acted quickly. *The Life Legal Defence Foundation* has filed a lawsuit to stop the implementation of the law, and *The Patients' Rights Action Fund* has launched a watchdog website of stories of alleged "mistakes and abuses" related to the new law.

A party to say goodbye for Californian artist Betsy Davis



In July, Californian artist living with Motor Neurone Disease, Betsy Davis, emailed her closest friends and relatives to invite them to a two-day party, with just one rule: No crying in front of her. The 41 year old held the gathering to say goodbye before becoming one of the first Californians to take a lethal dose of drugs under the state's new "End of Life Option Act (2015)".

Betsy had worked out a detailed schedule for the gathering on the weekend of July 23-24, including the precise hour she planned to slip into a coma. More than 30 friends had flown in from all

over the US to say goodbye. Betsy was then wheeled out to a canopy bed on a hillside where she took a combination of morphine, pentobarbital and chloral hydrate prescribed by her doctor.

Betsy's sister said family and friends understood how much Betsy was suffering and that she was at peace with her decision.



Report on VAD globally

On the website “Dying for Choice”, Neil Francis reports on a study recently published in the *Journal of the American Medical Association*, which reviewed the practice of assisted dying in lawful jurisdictions around the world. Researchers in the USA, the Netherlands and Belgium reviewed data from government and statutory authority reports, primary scientific studies and other sources to examine how assisted dying has been practiced in different jurisdictions around the world.

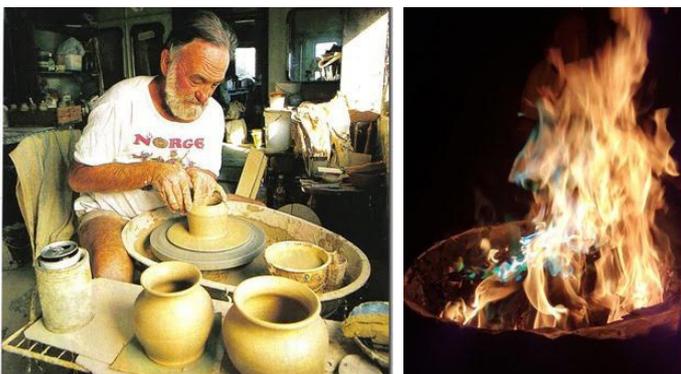
Their primary conclusion was: *“Euthanasia and physician-assisted suicide are increasingly being legalised, remain relatively rare, and primarily involve patients with cancer. Existing data do not indicate widespread abuse of these practices.”*

Key findings include:

- * VAD occurs everywhere, including jurisdictions where it is unlawful
- * Public opinion favouring VAD in developed countries has been increasing, or remained stable at high levels of approval. The trends seem to correlate with decreasing religiosity in these countries. The only place where assisted dying approval appears to be decreasing is in Eastern Europe, where religiosity has been increasing.
- * Approval of VAD amongst physicians seems to be consistently lower than amongst the public.
- * Most individuals who choose VAD have advanced cancer and ‘vulnerable’ groups are not represented in assisted dying figures at rates any higher than their presence in the overall population.

For more details see “Fact Files”, by Neil Francis, on the www.dyingforchoice.com website.

Thank you Graeme

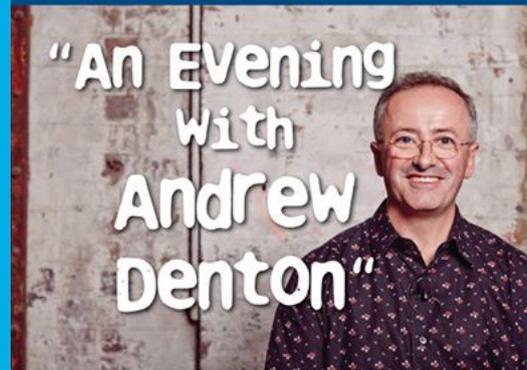


Our special thanks to Graeme Andersen (pictured), DWD NSW member from Lightning Ridge, who put his professional skills as a potter to create some beautiful pots for us. Graeme built the kiln, and for symbolism, lined it with old DWD NSW newsletters (from when we were still called the ‘Voluntary Euthanasia Society’), and did a special firing.

We are now the proud recipients of a series of very beautiful and original pots, which we are giving to guest speakers, and those who make a special contribution to our cause.

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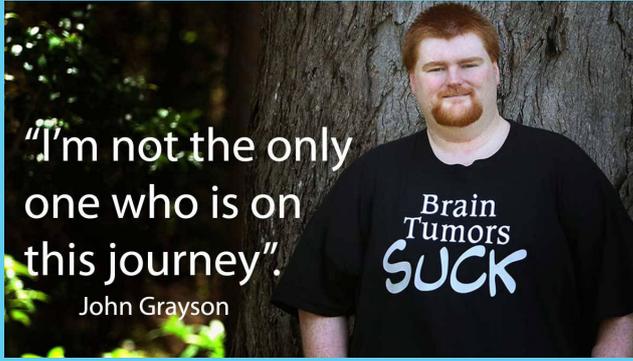
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John's story



John Grayson was 33 when he was diagnosed with a rare stage 3 malignant brain tumour. In August he appeared on the ABC TV documentary series "You Can't Ask That", which focused on the topic of terminal illness. John's answers were thoughtful, sanguine and funny at times, and the entire program was extremely moving. (Interestingly, all five terminally ill interviewees supported VAD).

John recently wrote a piece for the *Newcastle Herald*, in which he described how things have progressed since his story was first published in that newspaper 18 months earlier. He reflected on the 2015 filming of the ABC program: "When I first watched the episode on a preview link I felt a kinship with the members of the show. Their acceptance of death and their humour felt so familiar. It was my peer group. Tony Beks mentioned his fear of the pain, I have that same dread. I've had a single glimpse of that pain. When the show aired ...It finishes with the words: "In memory of Tony Beks, Jack Richards, Cory Taylor". Sod cancer. I can only hope their passing was swift and as pain free as possible." John explained in the article: "Make no mistake, I am going to die. Probably soon... Being alive but 'unaware' is a horrific idea for me. So I support the choice to die."

Testimonials from both Cory Taylor and John Grayson have been included in "The Damage Done" book by Go Gentle Australia, and John's is reproduced below:

In 2014 I had a cold. It was very painful and on 10 November 2014 I experienced the worst pain I ever had in my life (by magnitudes). I could only imagine that my eardrum had ruptured or something. By the 11th, the pain had only increased if anything. I wanted to go to the GP but I couldn't take myself there, so I asked my mother to drive. As we were in the carport I opened the car door and I collapsed onto the ground with a grand mal (tonic-clonic) seizure.

I was admitted into John Hunter Hospital in Newcastle where a large mass of approx 'very large chicken egg' size was found. It was a tumour. Shortly before

Christmas I received the pathology results: Grade 3, anaplastic, aggressive, malignant, ganglioglioma. Prognosis two to five years. I was 33.

For myself, I'm not afraid of death. Death is nothing, it's void, it's null. I'm no more scared of death than I am of the non-existence before my birth. What troubles me is pain. What troubles me is being alive but incapacitated. I've already felt that pain. It's horrific. I cannot put into words the feeling of that pain, that pressure pain. It's as though your entire brain is being forced out of your skull. In many ways that's what's happening. And pain meds can only treat that so far. Most opiates can't help it. Steroids are what they use, but they often have side effects.

As for losing my 'sense of self', I'm a hardcore nerd. I'm almost narcissistic to my brain. I like being a nerd. I enjoy knowing things. My greatest phobia is to lose my mind. So being alive whilst my mental ability goes, as my brain literally dies (grade 4 cancer is necrotic cells) will be unbearable.

The end game for my tumour, given that it's a left-side parietal tumour, is possibly: partial blindness, right-side paralysis, being mute, cognitive impairment, pain. I already get headaches about daily now. I get 'bad headaches' about every two to three days or so. I can generally push through these but, what happens when I can't? At the moment I just have to keep suffering and keep living.

So here's something that is rarely discussed with euthanasia. The lack of euthanasia laws depresses me. The fact that I know that, in my final days, I'm going to be forced to experience this torturous death is my greatest fear – depresses me. I'm spending my final years depressed not from 'dying' but from the 'method of dying'. If, however, we had euthanasia laws and I knew I could say, 'Right! When it gets to that point, I have a plan in place', I no longer would be worried. I'd be happier. I wouldn't have to face that torture. This is a very important point so let me state it again: euthanasia laws, by their existence, make terminal illness easier to live with.

I doubt the laws will be in place before I die, unless I get high on the bell curve for my cancer... Odds are on I'll have to figure out my own exit or I might get 'lucky' and die suddenly. But I hope that the more I can comment on it, and leave traces of my opinion – first hand – as someone living with terminal illness, hopefully people (politicians) will start to address this dire need for law reform.

by John Grayson from "The Damage Done"