

dying with dignity

SUMMER 2015-16 NSW



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website www.dwdnsw.org.au

PO Box 25 Broadway NSW 2007

Ph 02 9212 4782

email dwd@dwdnsw.org.au

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President's Message



First of all, a huge thank you to the many members and supporters who responded to our recent appeal for donations. At the time this newsletter went to press, we had raised over \$58,000 from 568 households, which is a response rate of almost 30%. The level of donations has totally exceeded our expectations, and I feel enormously touched and gratified by the generosity of so many of our members.

These funds will enable us to cover all of our expenses in the current financial year, and will contribute to our 2016 campaign. My most sincere thanks to all who contributed, and of course, if you would still like to make a donation, it is not too late to do so!

Who could have missed Andrew Denton's entry into the debate on Voluntary Assisted Dying (VAD)? Nothing is more compelling than having our arguments expressed by a well-informed, articulate and popular media figure. Denton described his findings, based on personal research in countries where VAD is legal (as well as in Australia), at the annual "Di Gribble Argument" event (see page 6).

The media responded, and Denton's views have now been very widely aired in print and digital media, radio and TV. A particularly important event was the ABC Q&A episode, aired on Monday 9 November (see page 8). The publicity generated through Denton's participation has exposed a very wide audience to the idea that VAD is an important issue, and has been safely legislated in overseas countries. We are enormously grateful for Andrew Denton's contribution, and appreciate his willingness to direct his energies towards promoting this issue.

Our campaign was also supported by Dr Helen Joyce, the International Editor of *The Economist*, who produced a lead story in support of VAD for their July edition. Joyce also spoke to a full house of the Sydney Opera House Drama Theatre as part of the "2015 Festival of Dangerous Ideas" about *The Right to Die: Why is the right to doctor-assisted dying supported by so many and legal for so few?*

Recent developments at both the state and federal level give us some cause for optimism. In NSW a cross-party "Parliamentary Working Group on Assisted Dying" was established in October. It has initiated the first steps of a complex process that will result in a new bill to legalise VAD being put before the NSW Upper House some time during the current parliament. By drawing on MPs from all major parties, as opposed to just one political party, the new bill will have an improved chance of success (see page 5).

On the federal scene, Greens Senator Richard Di Natale has confirmed plans to introduce the "Dying with Dignity Medical Services Bill", (co-sponsored by Alannah MacTiernan - Labor and Sharman Stone - Liberal), during the first half of 2016. This will engage federal politicians who were previously able to shun the issue by arguing that it was a state matter. It has been heartening to see some Federal MPs speak out in favour of VAD, including Deputy Labor Leader, Tanya Plibersek, Shadow Treasurer, Chris Bowen, and the Member for Fraser, Andrew Leigh (see page 11).

With Malcolm Turnbull having replaced Tony Abbott as Prime Minister, the atmosphere in Canberra has changed. Disappointingly, in a recent interview with ABC Radio Tasmania, Turnbull denied supporting law reform on VAD: *"It isn't a measure that I would support personally, but these issues have been considered in the past, and may well be in the future"*, he said. As a progressive on most social issues, it is hard to believe that this is Turnbull's genuine view. Hopefully his promise to be "agile" and "flexible" will apply to VAD too. (His wording actually leaves open the possibility of a rethink in the future). In spite of the Prime Minister's failure to embrace VAD, his leadership style (compared to his predecessor) may make it easier for MPs on the conservative side of politics to speak out in support of VAD.

Finally, you may have heard the exciting news that California has recently become the fifth US state to legalise VAD. This now means that almost one in six Americans live in a state where VAD is legal (Oregon, Washington, Montana, Vermont, California). This is important, not just for the people of California, but also for the movement towards change, because it reminds the rest of the world that VAD operates safely and effectively in a growing number of countries and legislatures.

We are looking forward to an exciting time in 2016, and once again thank you for your ongoing support.

Sarah Edelman
DWD NSW President

Treasurer's Message



I would like to echo our President's expression of appreciation for the very generous response to our 2015 fundraising appeal. The annual costs of operating our organisation are not covered by the revenue we receive from our membership subscriptions each year. We have managed to keep our membership fees at the same low rate for many years and the success of the recent appeal has meant that we have been able to offer 2016 membership at the same rate of \$50 (or \$25 for concession). Please keep in mind that you are always welcome to make a donation with your subscription payment to help us cover our costs.

All annual memberships are due for renewal on 1 January 2016 (unless you have already renewed for 2016). I encourage you to consider making a one-off payment of \$500, which will make you a Lifetime Member of DWDnsw and you will no longer need to worry about paying annual fees.

DWDnsw recommends that you make an advance care plan while you are well, or in the early stages of dementia. For the past few months, we have had a sub-committee looking at much of the public information on end-of-life planning. We have produced a "NSW Guide to Advance Care Planning". The 2016 Renewal Notice gives you the option to buy a set of printed advance care planning forms, including the guide, for \$20 (to cover our costs). These forms can also be purchased (or downloaded and printed for free) from our website. For those who do not need to renew for 2016 and do not have access to a computer, we have included a cut-out order form on page 14 of this newsletter. All new members automatically receive a set of printed forms.

Dying with Dignity NSW members are encouraged to keep their Membership Card in their wallet or purse, with the section on the back completed to provide emergency contacts and notice of where your advance care directive is located.

I look forward to presenting the DWDnsw 2015 financial report at our Annual General Meeting.

Philip Busfield

DWDnsw Treasurer

SAVE THE DATE

DWD NSW Annual General Meeting

Saturday 28 May 2016

1 pm to 3.15 pm

at the Sydney Mechanics' School of Arts

280 Pitt Street Sydney.

If you have skills and time available, you might like to consider nominating to be on the DWDnsw committee for 2016-17? If you would like to discuss this with us, please email your details and the best contact time to dwd@dwdnsw.org.au

Allied Group Reports

Port Macquarie Group



A large crowd of DWDnsw members and supporters attended our meeting on 24 November to hear Dr Rodney Syme. The audience welcomed the opportunity to ask questions and have their concerns clarified. The timing could not have been better, given the related television coverage recently on *Q&A*, *Insight* and *Dateline* programmes.

While in Port Macquarie, Dr Syme conducted Australia's first workshop for GPs about having an end-of-life dialogue with their patients. Eight GPs and eight Nurse Practice Managers attended. We are very grateful to the *Northcoast Primary Health Network* who promoted this event to GPs through their extensive database and provided the training room for the event. We are hopeful that more GPs in our area will be willing to help their patients with end-of-life planning.

Our next meeting will be on Tuesday 8 March 2016, when we will have guest speaker Debbie White, Nurse Practitioner Palliative Care. The following meetings will be held on Tuesdays 7 June, 6 Sept and 22 Nov 2016 at 10 am till noon at "The Pier" *Port Macquarie Panthers Club*, 1 Bay St, Port Macquarie. Everyone is most welcome.

Annie Quadroy

Port Macquarie Group Convenor
email: dwdpmq@gmail.com

Central Coast Group

On 27 November the Central Coast Co-ordinator, Bev Symons, presented her Annual Report to a full room at our last meeting for 2015. As she explained, it has been another very busy year for our group. It started in early January with lots of letter writing to all the local candidates for the March NSW election. In May our committee members made submissions to the Victorian "Parliamentary Inquiry into End of Life Choices" and we provided information sheets to members detailing how to make their own submissions.

We held four group meetings during the year, each one with an informative speaker, or two. In March we attended the *Women's Day March* and rally in Gosford. On August 30 members of our group attend a screening of the film 'Last Cab to Darwin', followed by a lovely lunch together.

2016 looks like being another big year for our group, as we support the progress of Di Natale's bill and that of the "Parliamentary Working Group on Assisted Dying".

Our meeting dates for 2016 are 19 February, 20 May, 19 August and 25 November 2016. At our February meeting we will have guest speaker Stuart Carter speaking on "Advance Death Care and Funeral Planning". All our meetings are on Fridays at 10 am till noon 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

Vale John Hogan

Our dear friend John Hogan, from the Central Coast group, died at home in the early hours of 4 December after a five year battle with bowel cancer. He was 71. At his side was his loving wife, Jessie Edney, and his adult step-son. His final hours were not peaceful and were very difficult for his family to watch.



John Hogan in 2011 just after he was diagnosed with cancer.

John was a DWDnsw committee member from 2011 to 2013, travelling down from the Central Coast to attend committee meetings in Sydney. He resigned only when his illness made this too difficult. He was a kind and positive man who

wanted to live as long as he possibly could, but strongly supported an individual's right to VAD. If the law in NSW was different today, John may have chosen for his life to have ended much more peacefully and without any risk to his family. The current and previous committee of DWDnsw and all the DWD group at the Central Coast mourn the loss of this lovely and courageous man.

There has been interest in setting up DWD meeting groups in Newcastle and in Illawarra/ South Coast NSW. This is only possible if we can identify key people who are prepared to nominate for the committee to lead and organise these groups, which would be run by volunteers. If you live in either of these areas and want to help set up a new group please email dwd@dwdnsw.org.au or phone 02 9212 4782.

Christians Supporting Choice for Voluntary Euthanasia (Ch4VE)

I was delighted to be invited to speak at the Victorian "Parliamentary Inquiry into End of Life Choices" (the Inquiry) on 15 October. This was in addition to the written submission made by our group. It gave us an opportunity to say more about Christian support for the choice of voluntary assisted dying (VAD) in appropriate circumstances.

It also gave me the opportunity to make a few brief observations on other submissions made to the Inquiry. For example, a number of submissions were form letters which included a prayer that God would influence the Victorian MPs not to approve VAD. I noted that "*Dr Olvera in California, whose young daughter died a terrible unnecessarily traumatic death from cancer, was also praying to God that God would influence the Californian MPs to approve assisted dying. Obviously this presents God with somewhat of a dilemma. Interestingly, the California legislation passed.*" (The transcript of the public hearing from the 15 October is on the DWDnsw website if you would like to read it in full).

If you have not already joined Ch4VE, please consider doing so. Membership is FREE. Simply advise your name and address by email iagree@christiansforve.org.au or write to me at Villa 1 / 4 Wills Place, Mittagong NSW 2575.

Ian Wood

National Co-ordinator and Co-founder Christians Supporting Choice for VE.

Voluntary Euthanasia Party NSW

By Shayne Higson
VEP NSW Convenor

I am often asked about the difference between DWDnsw and the Voluntary Euthanasia Party, so I would like to use this opportunity to explain.



Dying with Dignity NSW (DWDnsw) is a law reform organisation campaigning for a change in the law, so that individuals with unrelievable suffering will have the option to access medical assistance to end their lives peacefully, at the time of their choosing.

The Voluntary Euthanasia Party (VEP) shares exactly the same goal as DWDnsw, but we are a political party. The VEP stands candidates at both state and federal elections. Whilst we ultimately hope to get a member of our party elected to parliament, our campaigning in the lead up to every election also helps to draw public attention to this issue. We also want to provide an avenue for individuals who strongly support law reform for VAD to be able to express this preference at the ballot box.

I joined the party soon after its formation in 2013. Having watched my mother go through a painful and very distressing death, I feel passionately about this issue, and want to do everything I can to help bring about a change in the law. I also believe that participating in the political process is a powerful means of affecting change.

Many members of DWDnsw are also members of the VEP. By becoming a member of the VEP, or by simply voting for VEP candidates at federal and state elections, individuals who support law reform can send a clear message to the major parties that this issue is a top priority for them.

On 5 December Kerry Bromson, the National Convenor of the VEP, ran for the Lower House federal seat of North Sydney in NSW, but it was held by the Liberal Party. At the 2016 federal election, the VEP plans to run Senate candidates in every state and territory. We hope to continue doing so until an Australian parliament, state or federal, passes the legislation we all want.

Thank you for your support.

Shayne Higson

Email - Shayne@VEP.org.au

Mobile - 0428 326 358

Other NSW News

NSW Parliamentary Working Group on Assisted Dying

In October, the NSW Parliamentary Working Group on Assisted Dying (PWGAD) was established. The objective of the group is to prepare a bill to put before the NSW parliament that will achieve law reform on voluntary assisted dying (VAD), and to prompt discussion in the community about VAD. It is hoped that the bill will go before the NSW Upper House during the term of this Parliament. Very exciting news indeed!

The group, set up by Nationals MLC Trevor Khan, consists of himself, Ms Lynda Voltz MLC (Labor), Ms Mehreen Faruqi MLC (Greens), and Mr Lee Evans MLA (Liberal – Member for Heathcote). Being comprised of members from all four major parties will give the bill a better chance of success than previous bills prepared by a single party.



Trevor Khan (pictured), an ex-lawyer from Tamworth, now Deputy President of the Legislative Council and Chair of Committees, spoke at our 2015 DWDnsw Parliamentary Forum about his own experiences of watching his father suffer after a catastrophic stroke. Khan's father, an elderly retired doctor, had asked his son to help him die and this personal experience influenced Trevor's view that VAD should be legalised.

The next stage of the process will be for the PWGAD to propose a draft bill, which will go before a select committee. The committee will then conduct an Inquiry, hear submissions and make a report to parliament. Submissions to the Inquiry will be an integral part of the bill's success, and we will be contacting our members at this time to explain how they can help in this process.

The NSW PWGAD have set up a Facebook page, and you can track their progress. If you or a family member use social media, and have not yet pressed 'Like' or 'shared' this page, we would love you to do so, as this helps to promote the cause. See: https://www.facebook.com/nswassisteddying?ref=aymt_homepage_panel

Andrew Denton Speaks Out

Andrew Denton is widely recognised as one of the Australian media's genuinely creative forces. His interest in voluntary assisted dying (VAD) was inspired by his own experience of witnessing his father's long and painful death 18 years ago. During 2015 he travelled to three countries that allow VAD, listened to arguments for and against such laws, recorded hundreds of hours of interviews and drew his own conclusions.



Denton delivers Di Gribble Argument 2015 - photo C. O'Brien

On 29 October Denton presented the case for voluntary assisted dying (VAD) at the annual "Di Gribble Argument Dinner" in Melbourne. His presentation attracted a huge amount of media interest, including interviews on TV, radio, digital and print media. On *ABC Radio National Breakfast*, Denton told Fran Kelly that his research started in Adelaide at a big convention against VAD. This event provided the opportunity to speak with anti-VAD advocates from all over the world. Denton then took their arguments to overseas places with VAD, to see where truth lay. Denton concluded *"I came away with a strong sense that the arguments of those opposed to euthanasia are mostly distortions that fly in the face of the facts."*

Denton observed that the system currently operating in the Netherlands, Belgium and Oregon was very well thought through, with genuine safeguards. *"The greatest proof that they worked were enormous numbers of people across the political spectrum, and across all medical bodies that support the laws."* In response to concerns about abuse, Denton stated *"The key argument that I hear over and over again is that the elderly and the disabled are being made vulnerable, and I particularly explored that. I found that in these three countries, not only [was there] no evidence of that, but I also did something that I don't think was done before. I went outside of the system and spoke to representatives of the peak groups for disabled and elderly people in Belgium, the Netherlands and Oregon, and I put to them every single one of the warnings that I had*

been given about how their members were being abused, to see if they were true. And they were emphatic and universal in saying that 'no, there is no record of abuse'. None at all. And I came away with a very clear picture that putting the elderly and the disabled at the front of this argument is cynical politics."

With regards to palliative care, Denton told the audience at his Di Gribble presentation, *"Of all the things I learnt over the last eight months, the most shocking was this: there is one circumstance in which Palliative Care Australia will accept a patient's right to hasten their own death – which is to refuse treatment, including food and water, until they die. Seared into my brain is the conversation I had with Professor Richard Chye, the head of palliative care at St Vincent's – a gifted physician and teacher who, when I asked how long it can take for a patient to die this way, told me it could take weeks – weeks which were psychologically painful for both the person dying and their family watching on."*

"Are you thinking what I'm thinking? This is outrageous. I can hardly believe that we live in a country where it is ethically acceptable for a patient to choose a slow, painful death by dehydration and starvation, but ethically unacceptable for them to choose a death that is quick and painless. In what way is that alright? This is in such stark contrast to what I found overseas, particularly in Belgium, where Arsène Mullie, the former head of palliative care for Flanders, talked about euthanasia as an 'act of love' towards his patient. 'When someone is suffering,' he asked, 'how can I ask them to suffer more?'" (The full text of Denton's speech is on the DWDnsw website).

Denton is producing a series of podcasts, titled "Better Off Dead", based on his research in Australia and overseas. These will cover personal stories, arguments made by opponents and supporters of VAD, and reports of how the laws work in countries where VAD is legal. He hopes that the podcasts will be completed and available online from early 2016. Currently he has released two podcasts of his preview series, which are available to listen to from our DWDnsw website.

If you are interested in finding out the latest news between newsletters, please see our Dying with Dignity NSW website www.dwdnsw.org.au

ABC Q&A Discussion on VAD

In the last three months, Voluntary Assisted Dying (VAD) has been discussed on ABC's Q&A program on two occasions. The first was on 7 September, when the topic came up towards the end of the program. Panel members included Dr Helen Joyce (International Editor of *The Economist*), Geoffrey Robertson (International human rights lawyer), Mike Baird (NSW Premier) and Chris Bowen (Shadow Federal Treasurer).

A video question was asked by a 34-year-old viewer: *"My name is John Grayson. I'm 34 years old and I have a terminal brain tumour. My question is open to the panel. Before I eventually die, I am going to end up with right hand side paralysis, blindness, being mute. I will end up in severe, chronic pain. I will have cognitive impaired ability and then I will eventually die. What I want to know is why I'm forced to go through that torture. Why can I not put in place now safeguards that say when I get to a certain ability I can choose to end my own life? We do not force animals to go through that torture. Why do we force humans?" ***



This was powerful television. A young man (pictured), with a terminal illness, describing the predicted indignities along the way to his inevitable death, asking why he is denied the right to determine the manner and timing of his own death.

An interesting panel discussion followed. NSW Premier, **Mike Baird** stated: *"Look, it's such a tough subject this. I mean, I had very strong views, then in my first election campaign doorknocking I opened the door and a man ...shared his plight and the pain he was in, his wife right next to him, and he just pleaded with me that if I got in, that I would enable him to take his own life. Now, that will always haunt me. It is just such a terrible position, as we heard from the man in the video, on where his life is going, but the concern I have in this is that, you know, how do you put a definition around the quality of life and life itself? I think that, at the moment, we have a point that if anyone is off drowning off the coast, everything is done to save them. You know, we've got aircraft going, we've got vessels, anything*

that are going to save a life, and my concern is the unintended consequences if we went down this path, on what it might mean."

Geoffrey Robertson stated: *"We have a fundamental right not to be subjected to torture, and if that torture is cancer, if it's a terminal illness, we are entitled to take ourselves out of it. It is an awesome decision to make, but it's we are entitled to make it without the intervention of the state, without having those who assist us, often our loved [ones], arrested and charged with assisting suicide."*

Dr Helen Joyce stated: *".. there are places that are already doing this and it has not led to the sort of disaster that the fear mongers have suggested that it will. These are individual choices. There will certainly be people - many, many people - I would say the majority of people want to wring out the last drop they can, even in very limiting circumstances. That's fine. That's their choice. And then there are other people who feel that maybe those last few weeks, which may be in great pain or great discomfort, or extremely restricted, cast a shadow back over the rest of their lives and kind of ruin the end of it, or that they risk going into hospital and becoming completely incapacitated and not even getting to say goodbye to people."*

Shadow Treasurer, **Chris Bowen** stated: *"We need to tackle this. I think the matters that Mike raises, while legitimate, can be worked through, and they're worked through in every other country and you need all the checks and balances to ensure that it is a genuine decision, properly made, but we have to tackle this. It hasn't been discussed in the Federal Parliament for a long time. This should be on the agenda.... I would guess that there would be strong support on my side of politics for some sort of reform here but, you know, every MP would have their own process to go through to think through the issues and make sure that the checks and balances are appropriate. At the end of the day, it is about dying with dignity, which as Geoffrey made the point, is a pretty fundamental human right."*

... If only such common-sense prevailed amongst our politicians in Parliament!

** Dying with Dignity NSW has contacted John Grayson, and we have made a short video of him speaking about his wishes. We plan to use the video during our 2016 campaign.

ABC Q&A : “Facing Death”

On Monday 9 November, ABC’s Q&A ran a special episode on the topic “Facing Death”. The panel consisted of Andrew Denton and Dr Rodney Syme, arguing in favour of legalising voluntary assisted dying (VAD), two doctors opposed to VAD, Dr Karen Hitchcock and Dr Ralph McConaghy, and cancer patient, Ana Lamaro. It was compelling viewing.



Many DWDnsw members were in the audience, and some were able to ask a question to the panel. Rose Cox, talked about her mother, Caroline Cox (pictured), who has a progressive neurological disease and wants the right to be able to access an assisted death some time in the future. Rose asked the panel *“If we don’t have a law to allow my mum to request an assisted death, then what do my sister and I do if it reaches a stage where she asks for our help?”* Caroline Cox later added *“Well, they [my daughters] know that at some point in my life when things become intolerable and the pain becomes intolerable as I age, then I don’t want to stick around beyond that point, and I don’t think it’s really up to anybody else what I do with my life, just the way I’ve run my whole life. I think I should be able to choose that end.”*

DWDnsw member Sally Crossings asked: *“I have terminal illness, metastatic breast cancer. It can be held off for a while but there is no cure. While I’m well enough, I want to make sure that my dying will be the way I want it to be, not decided by anyone else. Not doctors, priests, palliative care teams, no matter how well intentioned. I want the supreme comfort of knowing my life can be ended if and when I decide enough is enough, and I’d like to be able to seek some professional help, as I do for other decisions. I respect the rights of other people who do not seek this option, but not their attempts to prevent me from making my own life and death choices. Can anyone put a cogent argument as to why I should be denied this choice?”*

In response to Sally’s question, Dr Karen Hitchcock raised the issue of state sanctioned killing by saying *“I guess euthanasia, for me, is more about the right for the State to sanction organised killing. It’s about*

the right to kill, and I think that that is the problem with euthanasia.” On several occasions Andrew Denton objected to the use of the word “killing” by opponents of VAD: *“No, that is not you killing. That is this lady making her choice. There is a right to have a choice about how you might die”.*

Denton dominated the episode with his detailed knowledge of published research, as well as personal observations and information collected whilst in Belgium, Oregon and the Netherlands. He repeatedly challenged the assertions made by Hitchcock and palliative care physician, Dr Richard Chye, that VAD means doctors are “killing” patients. When audience members opposed to VAD presented unsubstantiated claims of ‘abuses’ happening in countries where VAD is legal, Denton came back with facts and figures that challenged their assertions, while remaining remarkably calm, focused and congenial.



Andrew Denton challenges Dr Karen Hitchcock on QandA 9 Nov 2015

Dr Rodney Syme of DWD Victoria also presented some very powerful arguments for the legalisation of VAD. In response to a video question from Lawrie Daniel, who has progressive Multiple Sclerosis, Syme highlighted the comfort that choice provides to sufferers of neurological disease, and the limitations of palliative treatment: *“You can’t palliate paralysis. You can’t palliate the loss of function of bowel and bladder. It’s extremely difficult to palliate the psychological and existential suffering which accompanies this. For example, Motor Neurone Disease, a progressive disease which robs a person of the use of their legs and arms, gradually then coming up to affect their ability to speak, to swallow and ultimately to breathe and there is no palliation which you can give for this disease. You can support the person with physical aids and nursing care but, ultimately, this is a slow, tragic death If you give them control over the end of their life, you are giving them one of the most important palliative tools that they can possibly have because now, instead of suffering from that oppressive psychological and existential suffering, they know where they’re going. It is bloody hell every inch of the way but they know they’ve got the key to the fire escape.”*



Dr Syme (pictured) acknowledged that in 2005 he had provided lethal *Nembutal* to terminally ill cancer sufferer, Steve Guest, which he subsequently used to end his life. The police refused to prosecute, citing “lack of evidence”, in spite of Syme’s open admission. When asked by Q&A host, Tony Jones, “Are you actually trying to provoke the police to prosecute you?” Syme answered “Yes, indeed. Because I would argue that what I am doing in providing somebody with medication is providing them with very, very good palliation. If Ralph [the palliative care doctor on the panel opposed to legalising VAD] can help a person to die by providing them with ... [terminal sedation], and he is doing it to relieve their suffering, then I argue that I can provide a person with medication which provides them with palliation, relieves the psychological and existential suffering ... and I believe that is a palliative act.”

Q&A is one of the top rating ABC programs, with an audience of around 1 million viewers. To have these arguments conveyed so eloquently to such a large audience, helps to engage a growing number of Australians with this issue. This is important because the greater and the more vocal the public support, the harder it becomes for politicians to ignore this issue. There is no doubt that this program, together with Denton’s many other recent public appearances, have been enormously helpful in advancing our cause.

Follow-up Fact Check:

During this ABC Q&A episode, audience member, Luke Formosa, alluded to “*Findings from the Netherlands Euthanasia Report in 2014 indicate... 550 newborn babies with diseases or disabilities were killed.*” Denton responded: “*I completely dispute and question your assertion that 550 babies have been killed. Under Dutch law, there is a thing called the Groningen Protocol, which sounds very sinister but which, in fact, applies to very, very rare conditions of extreme spina bifida and a thing called EB, where your skin is literally flaking off, and it has applied to maybe a dozen babies. So I don’t know where you got that figure of 550 from but I think it’s not correct.*”

Independent online journal *The Conversation* later conducted a fact check on this assertion, with analysis from academic experts in the field. Their report concluded that there is no credible evidence to support Formosa’s statement that 550 newborn babies were killed. They concluded that “*While such claims appear on some websites, they are not backed by reliable official data.*” In fact, in 2010 there were two cases where physicians administered drugs to infants with the explicit intention of hastening death. In both cases, the physician’s actions were estimated to have shortened the babies’ lives by a week at most.



Some of the DWDnsw members who were in the audience at ABC Q&A on 9 November

U3A Talk Banned by Church

Many of you might have heard that Dr Sarah Edelman’s presentation “Dying with Dignity: Why Choice Matters” organised by University of the Third Age (U3A), was cancelled with less than 24 hours notice. The U3A Eastern Region runs its programs from the hall of the *All Saints Church*, Woollahra, and the minister in charge of that venue, Rev David West, notified U3A organisers on the afternoon before the scheduled talk that the presentation must not proceed. The event was open to U3A members, who do not have to pre-book, so some did know it was cancelled and came all the way there.

The story attracted articles in local papers (*City East* and *Wentworth Courier*) and the *Sydney Morning Herald*. In response to journalists’ questions, Rev West stated that the decision was prompted by a letter from an elderly man whose son had committed suicide “*after being involved in the group*”, and he was concerned that DWDnsw promoted self-harm. The journalist gave Edelman the opportunity to clarify that DWDnsw is an advocacy group that does not promote self-harm or give instructions on how to suicide (something we could have told Rev West if he had bothered to ask). In our view, the resulting media coverage was helpful to our cause, and reached a far greater audience than the presentation would have done. Most Australians support the legalisation of VAD and may not take kindly to the idea of censorship by a church official.

Other Australian News

Victorian Inquiry into End-of-Life Choices

In May 2015 the Victorian government stated its “Parliamentary Inquiry into End of Life Choices” (the Inquiry). A total of 1012 submissions were received, many from individuals who described their personal experiences of the death of loved ones. The Inquiry is presently conducting extensive hearings all over Victoria, and has spoken to hundreds of witnesses. It is due to present its report to parliament on 31 May 2016.



Of particular interest was evidence given by the Office of the Victorian Coroner. The Coroner reported that many suicides being referred were elderly people who were suffering multiple medical problems, severe pain and significant loss of quality of life. In the absence of an alternative, they were killing themselves, often in horrific ways. The Coroner reported that, in the four years between 2009 and 2012, 197 elderly people died this way.

The deaths fell into five groups:

- (i) people suffering terminal illnesses, usually cancer;
- (ii) people with multiple severe medical problems which were not immediately terminal;
- (iii) people suffering from severe degenerative disease such as Parkinson’s Disease;
- (iv) people suffering from uncontrolled pain over a very long period;
- (v) people who had suffered serious injury many years before, and for whom continued treatment was ineffective.

In all of these cases, mental illness did not seem to be a factor, with the vast majority being well supported by their families, and having stated their wish to die clearly, and on multiple occasions.

One case described by the Coroner involved an 82 year old lady: *“Her documented medical history: hypertension, insomnia, arthritis, gastro-oesophageal reflux disease, gout and on and on and on it goes. She was feeling very poorly about it, and depressed about her lot. Her vision was nearly gone. Her love of reading books,*

her quality of life was greatly diminished. She was described by her doctor as lonely, isolated, frustrated, impatient. ... She was found on the couch in her lounge room. This 82-year-old lady had a stained towel wrapped around her left hand. There was a knife on the floor in front of her, an open wound on her left wrist.... She died of exsanguination — she bled to death.”

Witnesses from the Coroner’s Office placed such cases into to the category of “non-preventable suicide”, saying that these are cases where there has been extensive medical intervention over many years, which was unable to halt the inevitable decline. Furthermore most of these cases do not qualify for palliative care, which is only brought into play in the final stages of a terminal illness.

Whilst the Coroner did not argue for legalisation of voluntary assisted dying (VAD), when reading all the evidence, it is difficult to avoid the conclusion that VAD would be the most reasonable option for some people to choose.

Full transcripts of most hearings are available at <http://www.parliament.vic.gov.au/lsic/inquiries/inquiry/402>

Senator David Leyonhjelm’s Push to Repeal Andrews Bill



On 2 December 2015, Liberal Democrat Senator David Leyonhjelm (pictured) introduced a private members Bill to repeal the *Euthanasia Laws Act 1997* (also known as the ‘Andrews Bill’). Whilst his bill would not reinstate the NT *Rights of the Terminally Ill Act*, its passage would send a message to states and territories that their legislatures can now turn their attention to voluntary assisted dying (VAD).

The Northern Territory (NT) was one of the first legislatures in the world to legalise VAD. *The Rights of the Terminally Ill Act 1995* came into effect in the NT in 1996 under legislation passed by the NT Country Liberal Party (CLP) government, led by Marshall Perron. Four NT citizens died using the provisions of the Act. The following year Liberal MP, Kevin Andrews, pushed the *Euthanasia Laws Act 1997* through Federal Parliament, which made it illegal for the ACT, NT and Norfolk Island to make laws in relation to VAD.

Strong support for repealing the NT legislation came at the time from predominantly religious and conservative members of both major parties, with Labor's Tony Burke (now Shadow Minister for Finance), showing rare collaboration with his Liberal counterparts in lobbying MPs to vote for the repealing legislation.

Andrew Leigh, MP, Declares his Support for Legislative Change



On 17 August, Federal Labor MP, Andrew Leigh (pictured), gave a speech to the House of Representatives, declaring his support for legalisation of voluntary assisted dying (VAD). Leigh, former academic and Professor of Economics at the

Australian National University, and author of several books on social issues, is one of the leading intellectuals in the federal parliament, and his public stance is most welcome.

Leigh's speech presents a number of well researched arguments. He cites Australian opinion polls that reveal widespread public support for end-of-life choices, and the large-scale international poll published by *The Economist* earlier this year, which found majority support in 13 out of 15 countries.

Leigh also cites the "Australia 21 Report", and evidence from a study published in the *Medical Journal of Australia*, that some doctors already do covertly hasten the death of particular terminally ill patients. According to Leigh, *"This is problematic because.... a law that applies to some and not others is arbitrary and against the spirit of equality. It therefore suggests to me that the current law is operating in a way that is deficient."*

Leigh also provides a human rights argument for legislative change: *"Morally, changing Australia's laws is about accepting patients' individuality, dignity and autonomy. I believe in the sanctity of life, but that belief in the sanctity of life is not a justification for denying choice for those who are terminally ill. This is about giving people a choice - a say - in how their death happens. I believe community attitudes have been changing for many years and it is time that politicians listened."*

It is heartening to see a federal Labor MP willing to speak out in favour of VAD, knowing that in doing so, he risks a negative campaign from religious groups. Hopefully, others will follow him.

Vale Ray Godbold



Ray Godbold with his wife Robyn. (photo:Jon Tjhia)

In August, 57-year-old Victorian palliative care nurse, Ray Godbold, died of gastroesophageal cancer. In the last years of his life, Godbold campaigned for law reform, and made headlines in May 2015 when Victorian DWD campaigner, Dr Rodney Syme, publicly presented him with a bottle of Nembutal. Godbold spoke to journalists at *The Age* and to radio personality, Jon Faine, about the reasons why the option of 'choice' was important to him. Godbold also recorded an interview with Andrew Denton, for Denton's "Better Off Dead" project to be launched in early 2016.

In the last month of his life Godbold could barely eat, and struggled to swallow. At 6 feet tall, he weighed 40 kg, and frequently fell, splitting his skin. The day before he died, Godbold made the decision to take the lethal *Nembutal*, but according to his family, was unable to swallow it. He was taken to the local hospital, where he died hours later. The DWD movement is grateful to Ray Godbold, for his willingness to talk about his own personal experiences in campaigning for legal change.

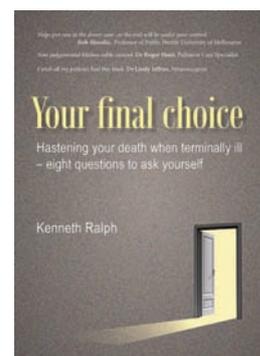
Book Review: "Your Final Choice: Hastening your death when terminally ill – eight questions to ask yourself"

By Kenneth Ralph

Review by Dr Liz Jacka, DWDnsw Committee

This new book on how to think about end-of-life decision making is a must-read. It is structured around the eight questions mentioned in the title.

Kenneth Ralph runs a private counselling service in Geelong and is trained in philosophy, theology and psychotherapy. In this book he calmly and rationally lays out the arguments for and against voluntary



assisted dying (VAD) in a highly sensitive and readable manner. He draws on a wide range of sources including medical research, psychology, philosophy, theology and legal research as well as a number of case studies from his own experience and elsewhere.

Though Ralph declares his own support for VAD from the outset, he gives due consideration to opposing positions. What is particularly valuable about this book is that the author is a person of faith (Christian) who argues cogently for the consistency of religious belief and a belief in VAD.

This book would be a superb introduction to the topic by people new to thinking about these issues, as well as a great starting point for anyone contemplating making an advance care directive. It should also be compulsory reading for our politicians as they begin to consider legislating to allow VAD.

It is available online from Morning Star Publishing Northcote Victoria for \$22.95.

International News

California USA

In early October, California became the fifth US state to legalise Voluntary Assisted Dying (VAD). With 12% of the US population, it adds a substantial proportion of Americans who are now protected by the legislation.

After a lengthy and emotional debate, the bill was passed by the Californian State Assembly in September, 42 votes to 33. Subsequently, there was still much speculation about whether California's Governor, Jerry Brown, would sign off on the bill, especially given that he is a committed Catholic and had training as a Jesuit priest.

Nevertheless, in early October he did so, saying *"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."*

Many have attributed this success to the highly publicised case of 29-year-old Brittany Maynard, the Californian woman with brain cancer who moved to Oregon to legally end her life in late 2014. Maynard put a 'human face' to the issue of VAD, and strongly influenced public opinion.



Ellen Pontac - a Californian supporter of the bill.

In 2015 bills to allow VAD were introduced in 23 state legislatures, up from just four in 2014. Pro-choice advocacy group, *Compassion & Choices*, campaigned to build public support for the Californian law, and then to persuade California's legislators and Governor Jerry Brown to back the bill. They collected endorsements from several city councils, including Los Angeles, and submitted sympathetic opinion articles to major newspapers. According to Barbara Coombs Lee, President of *Compassion and Choices*, personal stories will continue to make the difference in getting law makers' support.

New Zealand

The late Lecretia Seales might become the "Brittany Maynard" of New Zealand. Just as Maynard's personal story became the tipping point that got California's legislation over the line, so the case of Lecretia Seales may open the path to similar legislation in New Zealand. The case, which we reported on in our last newsletter, aroused a huge level of interest in New Zealand, and elsewhere.

Lecretia and her husband Matt Vickers (pictured) had a facebook page with 10,000 followers. Their supporters helped conduct a campaign which led to the presentation of a petition with 9,000 signatures to Parliament. The text of the petition read *"That the House of Representatives investigate fully public attitudes towards the introduction of legislation which would permit medically-assisted dying in the event of a terminal illness or an irreversible condition which makes life unbearable."*



As a result, a New Zealand Health Select Committee has been established with what Matt Vickers describes as disappointing terms of reference. At least the issue is firmly on the table.

Several earlier voluntary assisted dying bills in had failed in New Zealand, but they were private members' bills, which did not pass to a second reading. This time, the matter is being considered by a parliamentary committee, and so may have a greater chance of success.

Although personally sympathetic to the cause, Prime Minister John Key has said that it will never come before the parliament as a government-sponsored bill because "it is a matter of individual conscience". Key also predicts that such a bill would be very difficult to get through because of strong opposition from within the National Party.

The UK

Despite massive public support for voluntary assisted dying (VAD), a bill known as "Lord Falconer's Bill" was overwhelmingly defeated in the UK House of Commons in September (330 against, 118 in favour). This was the first time that VAD had been voted on in the House of Commons in over 20 years. There had been overwhelming support for the bill among members of the public and the UK media, so many had been hopeful that the bill would pass.



People for and against Lord Falconer's Bill campaigned outside UK Parliament during the vote.

Prior to the vote, the former Archbishop, Lord Carey, had stated that allowing doctors to help terminally ill people to die would be a "profoundly Christian and moral thing to do". He rebutted the position commonly held by opponents that enduring pain at the end of life is ennobling. His remarks put him at odds with the Anglican Church.

In June the reputable journal *The Economist*, commissioned an *Ipsos Poll* in fifteen countries to determine the level of support for VAD. It found that only two countries, Russia and Poland, had less than 50% support. The International Editor of *The Economist*, Dr Helen Joyce, also wrote a passionate editorial in favour of VAD.

Following this, the prestigious medical journal, *The Lancet*, published a long article in favour of VAD, and a poll conducted by the conservative

Mail on Sunday (which had editorialised against VAD) found that two-thirds of older Britons think the Swiss VAD clinic, *Dignitas*, should be allowed to operate in the UK. They believe the law should be changed so people can choose to end their lives here by taking a lethal dose of drugs even if they are not terminally ill. Other newspapers, such as *The Independent*, also came out in favour.

The final vote was a major disappointment for supporters and campaigners.

Canada



In October Justin Trudeau (pictured) led the Liberal Party to a decisive victory in the Canadian elections. Trudeau has spoken out strongly in favour of legislation to permit and regulate voluntary assisted dying (VAD). In November, Canada's newly appointed Attorney-General, Ms Jody Raybould, announced that navigating the future of the new VAD laws would be at the top of her priority list.

In February 2015, the Canadian Supreme Court struck down the law criminalising VAD and ordered the federal government and the provinces to introduce legislation to regulate the practice. However, the previous Canadian government under Conservative Stephen Harper had been engaged in delaying tactics.

The Canadian Medical Association finally came on board at its annual meeting in August. Although many individual doctors indicated their unwillingness to participate, doctors' organisations as a whole have accepted the reality, and have helped in drawing up guidelines for the assessment of patients who request VAD.

A federally appointed panel is looking into legislative options to govern the practice, and a joint parliamentary committee may also assist with recommendations for legislation. Nevertheless, the Trudeau government is considering seeking an extension in the Supreme Court of Canada of its February 2016 deadline for amending the criminal code to protect doctors who offer VAD.

Quebec

In June 2014 Quebec (a province of Canada) passed a bill to allow voluntary assisted dying (VAD), which was due to come into effect on 10 December 2015. At the time it was passed, a number of supporters feared that the conservative Canadian government would try to overturn the legislation. However, the change in the Canadian government and the Canadian Supreme Court ruling allayed those fears

Earlier this year the majority of palliative care facilities announced they would refuse to cooperate with the new law, but their attitude appears to be softening. The first of the palliative care facilities, *La Maison Aube-Lumière* in Sherbrooke, Quebec, has announced that they will offer VAD for exceptional cases of cancer only. No doctor or medical personnel will be compelled to participate, but training for supportive doctors and staff began in November. Quebec doctors have been preparing for the practice to commence, with *The College Des Mediciens du Quebec* preparing a step-by-step guide on how doctors should approach people asking for VAD. The pharmaceutical industry has been producing kits containing the three recommended medications.

However on 1 December, a Quebec Superior Court Justice granted an injunction to the "Coalition of Physicians for Social Justice", a Quebec-based group of doctors opposed to the law. The injunction will block the commencement of the VAD laws in Quebec until at least February 2016.

The Quebec government continues to back the new laws, and has sought leave to appeal the ruling.

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(NB: If you need to renew your DWDnsw membership for 2016 please order ACP forms on your renewal form only)

Please post your completed form to DWDnsw at PO Box 25 Broadway NSW 2007 or scan it and email the copy to us at dwd@dwdnsw.org.au

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Lesley's Story by Hugh Sykes

My wife, Lesley Sykes, died of metastatic breast cancer on Saturday 11 July 2015. She was 69 years old.

Looking back on her life I'm so proud of Lesley. She was a teacher for 40 years and taught over 5000 girls. She was always held in high regard by both colleagues and pupils, who achieved excellent HSC results. Lesley was the mother of two children and the grandmother of four. She loved being a grandmother. She was also a highly skilled wood craftswoman. Since her retirement, we happily ticked off our bucket list, including extensive overseas travel.



Hugh and Lesley Sykes

Lesley's battle with breast cancer commenced in 2002. Following her diagnosis, she had a mastectomy, which at the time we believed had solved the problem.

She got on with her life until 2011, when a small lump appeared on her neck. It turned out to be a secondary tumour. Scans showed that there were too many tumours to be removed surgically, so Lesley began treatment with an estrogen-reducing drug which temporarily halted the cancer.

The cancer started spreading again in 2014, so she was prescribed two drugs that were taken together, but they caused terrible side effects – crippling headaches, abscesses and cellulitis. Lesley also tried three types of chemotherapy, but all failed.

In the last six months of her life, Lesley battled pain, weakness, immobility, lymphedema in one arm and both legs. Lymphatic fluid accumulated and seeped through the skin causing sore skin lesions and frequent change of dressings. Tumours growing in her shoulder muscles were very painful. Drugs reduced, but did not eliminate her pain and discomfort.

By April this year it became clear that she was going to die - there was no hope of a cure or halting the disease. Cancer is a cruel executioner. Tumours encircled Lesley's neck, blocking her windpipe and restricting blood supply to her brain. At one stage, her mental function was severely impaired because the powerful medications were affecting her brain. The tumours also made eating very difficult, and she could no longer eat solid food.

In the hospital most of the nurses were kind and capable. However, some were not. We realised the importance of having a family member present to advocate on her behalf, to make sure that she would always be well looked after. In the last two months of her life Lesley needed someone to shower her, take her to the toilet and help her manage personal bodily functions. For a normally active and independent person, this was humiliating and distressing.

Lesley was completely helpless in the last week of her life. She did not want a slow, miserable death, but she did not have a choice. She had earlier described her ideal death in an article published in "Mama Mia", written by journalist Shelly Horton: *"What I long for is to have a happy farewell party with friends and family here in my hospital room, and after they have gone, to be able to take the appropriate pills or injection to put me quietly into the final peaceful sleep."* My family and I, as well as many of Lesley's medical and nursing staff believe that she should have had that option.

Lesley died on 11 July 2015. We were able to say goodbye, but I am left feeling very sad that she had to endure the pain, discomfort and indignity of the last three months of her life. I would not wish it on my worst enemy and certainly not on the wife that I loved.

Please tell us your story

We are seeking people who have their own story to tell. We are keen to interview people who are personally affected by the current laws, and who would like to see voluntary assisted dying become a legal option in Australia. If you, or someone you know, is dealing with a terminal or serious incurable illness, and would be willing to talk about it, please contact DWDnsw via email dwd@dwdnsw.org.au or phone 02 9212 4782

My Story by Heather Bell



I am a 21 year old medical student at Western Sydney University and I have spent the last two years learning about how to prevent, detect, cure or delay disease. Almost every day, our teachers remind us of the immense responsibility that comes with practising medicine - that our patients will trust us with their lives, and we in return, must respect and honour that responsibility.

Eight weeks ago, I was presented with a medical problem that had no medical answer. It only had a political answer, and that answer was 'no'. That answer has been justified by politicians on many occasions and in many ways, but at its core is their belief that life is sacred and not ours to take. I contemplated that answer a lot as I sat with my mother, watching her being tortured by a cruel disease that was slowly taking her life.

Mum was diagnosed with a terminal neurodegenerative disease ten years ago, when I was 11. For the last year she was in a nursing home, severely disabled by her illness. She died eight weeks ago, aged 53.

I watched my mother writhe and scream in pain for an entire week before she died. Sitting by her bed, I looked on helplessly as she groaned and waited for the night nurse to administer a measly 5 mg injection of *morphine*. Any more could be fatal! I fed her spoonfuls of a special viscous water gel designed for those who cannot swallow, in an attempt to soothe her cracked and swollen tongue, and her ulcer-riddled mouth. And every moment I was racked with guilt, because there was nothing I could do to end her suffering.

Mum desperately wanted to die, and she repeatedly communicated this to me, her best friend and the nurses. Until even speaking became too difficult. For those last seven days I slept on the floor next to her bed. She lay there, sunken skull and razor sharp bones visible under her skin, weighing less than 35 kilograms. Her groans throughout the night amplified into screams every two hours, like an alarm clock, signalling time for her next *morphine* injection. I wiped her down with cool towels when her fevers hit, wiped the blood off her cracked lips, and wiped the pus and mucous out of her eyes as she sobbed.

Now she is gone, but I have no peace. I see her in my dreams, still in pain, needing help. So I rage at the heartless old men in the musty chambers of Parliament House, who forced her to suffer until the end. Those members of parliament who voted "no" because they believe that "life is sacred", or because they were pressured by others who have this belief. Deals are done, and conscience votes are voted on without conscience.

I will never forgive those politicians who claim to speak for the majority of Australians, but do nothing of the sort. I don't forgive them for forcing me, at age 21, to witness my mother's prolonged agony. I don't forgive them for the nightmares and the guilt I must now live with. And I don't forgive them for the lasting memories of my mother, which will always be of her suffering.

I cannot believe that any person who witnessed my mother's passing could say that the current system is working well. In its defence, I have heard it said that "some doctors already help their patients to die when their suffering cannot be relieved, so why change the system?" But how well is it working when these brave doctors must break the law and risk prosecution? And how well is it working, when the option is available to some but not others?

In three years' time I will be a doctor, and I wonder how I will react if I am faced with a patient in these circumstances. I still live in hope that during the next few years we will get laws that value the person more than "sanctity of life", and will leave it up to individual patients to decide when they have had enough. When all options are exhausted and suffering unbearable, the right to a voluntary assisted death should be a basic human right.

The activities of DWDnsw include public education campaigns, community talks, parliamentary forums, media publicity, liaising with and lobbying of politicians, providing information on advanced care directives, monitoring and reporting of overseas developments, communicating with pro-choice advocates overseas and collecting resources that help to advance our important cause.

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