

# dying with dignity

## WINTER 2015 NSW

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PO Box 25 Broadway NSW 2007  
website [www.dwdnsw.org.au](http://www.dwdnsw.org.au)

Ph 02 9212 4782

Fax 02 9211 1498

email [dwd@dwdnsw.org.au](mailto:dwd@dwdnsw.org.au)

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## President's Message



We had a very busy few months in the lead up to the NSW state election, communicating with sitting and aspiring MPs, and developing a database documenting how each Lower House member stands in relation to legalisation of voluntary assisted dying (VAD.) Thank you to all our members who wrote to politicians and forwarded us their responses. The "Pollies Register" is a significant achievement, and will continue to be a reference point in our coming campaigns.

Our Parliament House Forum, held in late February, enabled us to promote the "Pollies Register" and get out some key messages about the disconnect between public opinion and political intransigence. We have developed good relationships with some state politicians, and will continue to work with them during the term of the new government.

During our pre-election campaign, we were well supported by our regional DWD groups and the *Christians Supporting Choice for Voluntary Euthanasia*. They were very active in letter-writing and engaging with politicians. Shayne Higson mounted a strong election campaign for VEP NSW, and attracted good media attention to the issue of assisted dying. (See "Allied Group Reports" from page 4.)



Dr Rodney Syme speaking at our AGM in May

We had a very successful AGM on 23 May, with a large and enthusiastic audience. Happily, most of our 2014-15 committee have renominated, apart from Leslie Jolley who has moved out of Sydney. Three new members have joined our committee: Judith Daley (who joined the committee in February to replace Leslie), Greg Smith and Janise Farrell. Together they bring new skills,

talents and experience to the committee, and we are delighted to have them on board. (For more details of our 2015-16 DWDnsw committee see the "About Us" section of our website.)

The highlight of the AGM was the address by Dr Rodney Syme, Vice President of DWD Victoria. Rodney described some of his personal experiences with hopelessly ill patients that led him to become a passionate advocate for end of life choices. He also talked about his decision to provide Nembutal to terminally ill patient, Ray Godbold, and the baffling decision by *The Royal Australasian College of Physicians* to "un-invite" him as a guest speaker at their Conference. (See pages 6 and 7 for details, and page 10 for an extract of a published opinion piece by Dr Syme.)

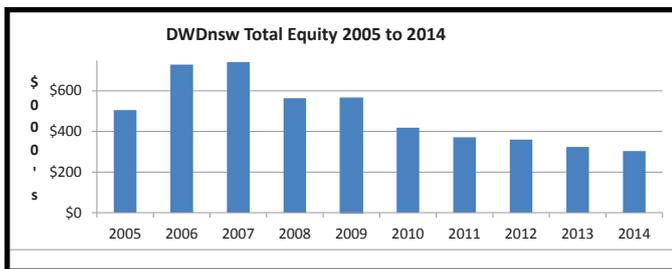
There have been further positive developments overseas, with Colombia now joining the growing list of countries that have legalised VAD. In California, VAD legislation has come one step closer following the passing of the *End of Life Option Bill* in their State Senate. (It is now due to be debated in their State Assembly.) After 30 years, the California Medical Association has just dropped its opposition to VAD. In South Africa, a High Court judge has ruled that a terminally ill man had the right to receive medical assistance to end his life. (See details in "International News" pages 11- 15).

Meanwhile, I have heard many comments about the *Sydney Morning Herald* opinion piece in May by psychologist, Mary Ticinovic. She argued that much personal growth and strength arises from people's suffering, even at the end of life. Arguing that, for the dying patient, there are benefits in enduring suffering is a hard message to sell, and judging from online comments and Letters to the Editor, has done more to advance our cause, than weaken it.

Finally, in what might seem an unrelated development, there was an overwhelming "Yes" vote in the Irish referendum to legalise same-sex marriage. While marriage equality and VAD are separate issues, there are many parallels; both are human rights issues, widely supported by the majority of Australians, but disallowed under current laws; both are barometers of the degree to which a society is tolerant and open-minded; and both are staunchly opposed by religious groups, who lobby politicians against their legalisation. The Irish result has increased momentum for marriage equality laws in Australia, and now legalisation appears much more likely. This would help progress the campaign for assisted dying by demonstrating that legislative reform is possible, in spite of strong opposition from religious groups.

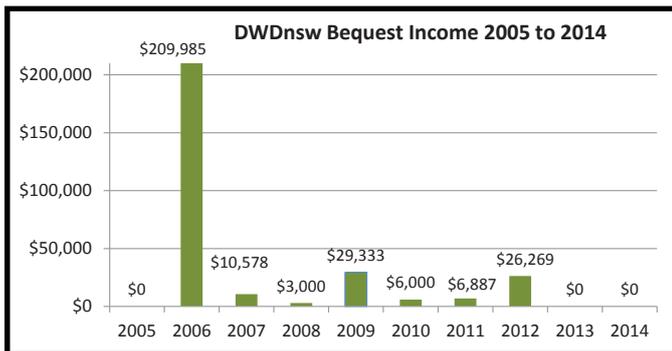
## Please Consider a DWD Bequest

Whilst most of our attention is focused on lobbying and planning strategies, at the back of my mind there is always some concern about our financial position. In order to survive, DWDnsw needs to have sufficient funds to be able to keep paying our bills. Our expenses include wages, office rent, electricity, phone, internet, website management, printing, postage, stationery, auditors, insurance, publicity and other minor expenses. Although we are very cautious with our spending, we generally have a year-end loss, as our income is lower than our operating expenses.



As shown in the graph above, our total equity has been falling since 2007. We have managed to keep the annual reduction to a minimum via various fundraising activities, increasing membership fees (in 2012) and reducing our staff numbers. In 2014 the drop in equity was a relatively small \$10,424.

Nevertheless, by the end of each year we have less available than at the start, and without an additional source of funds, we may run out of money before we accomplish our mission.



Historically, apart from the high interest and trust distributions received prior to the 2008 *Global Financial Crisis*, the most important contributor to our equity has been bequests.

A bequest is a donation paid from your estate after you have died. As shown in the graph above, we received a very large bequest in 2006, which gave DWDnsw great financial security for many years. Since then, we have received some smaller bequests, which further boosted our funds. In 2013 and 2014 we received no bequests at all.

In December 2013, I made a will, and included a substantial bequest to DWDnsw. When I die, DWDnsw will do quite nicely. I am now appealing to our members and supporters to consider doing the same.

A bequest of \$10,000 or more would make a significant difference to our financial position, especially if many of our members were to take this step. A bequest is a great way of contributing to our organisation when your current funds are limited. For the purpose of making a bequest, the registered name of our organisation is DYING WITH DIGNITY NSW and our Australian Company Number is 002 545 235.

The best way to ensure your will is legal and does what you intend is to have it drawn up by a solicitor or the *NSW Trustee and Guardian*. If you already have a will, adding DWD NSW as a beneficiary does not require making a new one. You can simply add a "codicil" to your existing will, specifying what you would like changed or added. If you, or your solicitor, have any questions about making a bequest, you can contact our office on (02) 9212 4782 or email [dwd@dwdnsw.org.au](mailto:dwd@dwdnsw.org.au).

Without the generous support of so many of our members we could not exist as an organisation. Thank you to all for considering the option of a bequest, as well as to those who have generously donated in the past, or who might do so in the future.

Yours in solidarity,

*Sarah Edelman*

*DWDnsw President*

### DWDnsw Committee 2015-16

- President - Dr Sarah Edelman
- Vice President - Dee Johnson
- Treasurer - Philip Busfield
- Judith Daley
- Janise Farrell
- Helen Harris
- Dr Liz Jacka
- Greg Smith
- Rev. Geoffrey Usher

### STAFF

Gabrielle Brown - Office Administrator

# Allied Group Reports

## Voluntary Euthanasia Party NSW

By Shayne Higson

VEP NSW Convenor and 2015 Lead Candidate



Shayne Higson and Caroline Cox campaigning on election day in Strathfield

The Voluntary Euthanasia Party (VEP) is a single issue political party with the same goal as Dying with Dignity NSW.

The VEP contested seats in the NSW Upper House in the recent state election. The party polled 40,971 primary votes, which represents 0.2 of a quota or 0.94% of the vote. This placed us in 8th place out of the 24 parties (or groups) contesting seats in the Legislative Council (LC). Of the 19 parties (or groups) who were not represented in the LC before the election, the VEP received the third-highest primary vote.

The NSW Electoral Commission distributed preferences and it took 391 counts to finalise the results. As the VEP Lead Candidate, I was still in the running right up until Count 388. This means that out of the 394 candidates who contested the 21 seats in the Legislative Council, I came 25th.

The last four Upper House seats were decided at count 391 and interestingly, they all achieved their seats without reaching a full quota.

It is now four years until the next NSW election, so where to from here? The VEP intends to keep voluntary euthanasia as an election issue into the future. It was always going to be difficult for a new minor party to gain a seat in its first attempt in NSW. However, considering that the *Animal Justice Party* achieved the last seat with a total of only 91,420 votes after preferences were allocated, and the fact that before being eliminated I had a progressive total of 43,896 votes, it would not be impossible for the VEP to achieve success next time.

As the Convenor of the NSW branch of the VEP, and given that I ran as their Senate candidate in the 2013 Federal election, it is likely that I will be involved in the next Federal election (although not necessarily as the Lead Candidate.) Every time the VEP contests an election our results get stronger. Although some people feel we will never achieve a seat in an Australian Parliament, I do believe our existence keeps pressure on politicians to support the issue of VAD.

On behalf of the VEP NSW committee I would like to say thank you to those DWD NSW members who either volunteered on election day, spread the word to friends and family, or simply used their vote to help send a message to the major parties.

*Shayne Higson*

Email - [Shayne@VEP.org.au](mailto:Shayne@VEP.org.au)

Mobile - 0428 326 358

## Port Macquarie Group

On 14 March the Port Macquarie DWD group hosted a Q&A Forum. The event attracted more than 400 people, some travelling from Sydney, Central Coast, Bowral, Great Lakes and Nambucca to attend. Panel Moderator, Mr Tony Delroy of *ABC Radio Nightlife*, expertly channelled over 30 questions to the panel, which included Dr Rodney Syme (Melbourne), Dr Frank Brennan (Sydney), Senator (Dr) Richard di Natale (Geelong), Dr Sarah Edelman (Sydney), as well as local political candidates and members. We hope to release our video of the event soon.



The overwhelming majority of the Q&A audience were in favour of legalising choice for voluntary assisted dying by the terminally ill. Despite being told not to attend the event by the *Mid North Coast Area Health Service*, about 60 general and palliative care nurses came along and were acclaimed for their professional efforts.

Dr Rodney Syme also presented two *End of Life Choices* workshops in Port Macquarie. These were well attended and the feedback was excellent. One outcome of the event was that two local doctors contacted DWD requesting permission to

use the Advance Care Directives given out by Dr Syme at the workshops. This approach has led to partnering with the *Mid-North Coast Medicare Local* to organise a GPs-only professional development workshop, accredited by the *College of General Practitioners* for Wednesday, 2 September 2015. Dr Rodney Syme has agreed to return to Port Macquarie to present the workshop. We understand that this will be the first time in Australia that such a workshop will be held.

Dr Syme has also agreed to be Guest Speaker at the meeting of the DWD Port Macquarie Group on Friday, 4 September 2015.

The high media exposure and success associated with the *Q&A Forum* and *End of Life Choices* workshops continues to attract new members and supporters, now approaching 400 for our region! We are very pleased that so many people are taking an interest in our campaign. As about half of these people do not have email, Bruce Gibbs, a key member of our Leadership Team, has set up an inexpensive system to send group messages to mobile phones and landlines.

At our meeting on 26 May, we had 68 attendees, including more newcomers. The guest speaker, Jill McDonnell, Aged Care Advocate/Education Officer of the *Aged-Care Rights Service Inc (TARS)* and *Older Persons' Legal Service (OPLS)*, was excellent. We are delighted that *Port Panthers* has agreed to continue to provide our meeting venue free of charge. We will be establishing political lobbying and media response "letter writing circles" to ensure that politicians regularly receive letters and that any regional media on the issue is responded to within 24 hours. We are pleased to have received requests for assistance from people in other NSW localities to help them establish similar groups in their area.

*Annie Quadroy*

*Port Macquarie Group Convenor*

*email: dwdpmq@gmail.com*

## **DWDQ - Gold Coast Group**

Some of our Northern NSW members may be interested to hear that the very enthusiastic Kerry Jackson has given new life to the DWDQ group on the Gold Coast with a "revival meeting" late last year. For more information, please contact Kerry on 07 5532 1552 or 0408 747574 or email [kerryjackson2003@yahoo.com](mailto:kerryjackson2003@yahoo.com).

## **Central Coast Group**

In February, the Central Coast group prepared for the NSW election with a "*Meet the Candidates Forum*". In the weeks prior to the meeting a questionnaire on legalising voluntary assisted dying was sent to candidates in the four local electorates. The positive responses from many of the candidates helped produce a fruitful discussion on the day. All responses were included in the DWDnsw "Pollies Register".

Our May meeting was entitled "*Estate Administration and Executor's Duties*". Guest speaker Trevor Booth, Manager, *NSW Trustee and Guardian*, Gosford Branch, provided very good information about wills, power of attorney and enduring guardianship.

The upcoming Central Coast group meeting dates are August 21 and November 27. They will be held 10 am to 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*

## **Orange Group**



We will have our next meeting on Thursday 11 June from 10 am to 12 pm at the *Home and Community Centre*, 286 Lords Place, Orange. We have a guest presenter who will speak about funerals, including "eco-burials". We are encouraged by the positive feedback we have received after previous meetings. Our support for voluntary assisted dying legislation is discussed at the beginning of each meeting.

We hope to encourage others to come on board to expand our core group and bring fresh ideas for promotion of DWD. Due to the unpredictable and cold weather conditions, our next meeting after June will be Thursday, 15 October, from 10 am.

All the best from us in Orange,  
*Bev, Heather, Cheryl, Kate, Kay and June*

(All enquiries to Heather on 02 6361 0913  
or Bev on 0414 842 078).

## DWD ACT Inc.

Our meetings are held at the *Grant Cameron Community Centre* at 27 Mulley Street, Holder. Everyone is welcome. See our website for the latest ACT news [www.dwdact.org.au](http://www.dwdact.org.au)

*Jeanne Arthur*

President DWDACT

PO Box 55, Waramanga ACT 2611

## Christians Supporting Choice for Voluntary Euthanasia

Currently our group has a volunteer from each state contacting Senators in the Federal Parliament to try and ascertain if they support 'in principle', Senator Richard Di Natale's *Dying with Dignity (Medical Services) Bill*.

Given the wide terms of reference, I believe the decision of the Victorian Parliament to refer "end of life choices" to a Parliamentary Committee is a good one, provided it is not just an excuse to procrastinate! I encourage our members across Australia to make a personal submission via [www.parliament.vic.gov.au/lsic/article/2609](http://www.parliament.vic.gov.au/lsic/article/2609) to show your support for VAD legislation.

Interested readers can find our Annual News Update at <http://christiansforve.org.au/news/>

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](mailto:iagree@christiansforve.org.au) or write to me at Villa 1 / 4 Wills Place, Mittagong NSW 2575.

*Ian Wood*

Co-founder Christians Supporting Choice for VE.

## Other Australian News

### Dr Syme Pushes Boundaries Once Again

On 11 May "The Age" carried an article by journalist, Konrad Marshall, describing the circumstances of terminally ill cancer sufferer, Ray Godbold, aged 59. Godbold has stage 4 gastroesophageal cancer, which had spread to his liver and lymph nodes. As the cancer is progressing he is experiencing more distressing symptoms, including pain and loss of energy.

Godbold was a palliative care nurse, so he knows what a bad death looks like and he does not want that for himself. Godbold does not want a drip of Morphine and Midazolam to send him into a coma. He does not want strangers making decisions about his death while he is unconscious, with his family sitting for hours, days or even weeks – waiting for his last breath. He wants control over the manner and timing of his death.

Godbold has met with Dr Rodney Syme to discuss the final stage of his life and his desire for control over how his disease will unfold. Dr Syme has very boldly and publicly provided Godbold a bottle of Nembutal, which will enable him to end his life peacefully, if he chooses to do so.

"That's medication for you – some Nembutal," Dr Syme says, "You need to take that by mouth, and you will have total control of that. It's not my intention that you take it. I hope you don't need to take it. But if you run into a brick wall, then that is what I sometimes call the key to the fire escape."



Ray Godbold, with Dr Rodney Syme, and a bottle of Nembutal

In Victoria, it is a criminal offence to incite, aid or abet a suicide, with a maximum penalty of five years' jail, yet no Victorian doctor has been charged in the past 50 years.

By taking this very public stand, Dr Syme is once again daring authorities to prosecute him. He is mounting a public challenge to current laws that deny people the right to access medical help to end their own life in a peaceful and reliable way.

At age 79, Dr Syme is not keen for a legal battle or the possibility of prosecution, however he is willing to do whatever it takes to highlight the fallacy of current laws. High profile cases reported in the media have the potential to engage large sections of the population and if Dr Syme is prosecuted, the story may well generate a public outcry. In NSW, Premier Barry O'Farrell's introduction of tough laws to combat alcohol fuelled violence demonstrated that sometimes politicians are forced to act when public pressure upon them becomes too great.

## Royal Australasian College of Physicians Stifle Debate

In February, Dr Rodney Syme received an invitation from the Royal Australasian College of Physicians (RACP) to deliver a plenary address at their annual conference, to be held in Cairns, 24–27 May. His paper, titled *“The gap between the rhetoric and the reality of palliative care”* had already been prepared, and his travel arrangements had been made, when just two weeks prior to the conference, Dr Syme received notice that he was being “un-invited”.

According to conference organisers, the decision was “regrettable” and made after “careful consideration”, but it “accurately reflected the membership’s feedback.” However, the College refused to specify who had made the complaint, or what proportion of its membership the complainants represented. Ironically, the title of the conference was *“Breaking Boundaries, Creating Connections”* and the conference programme proclaimed *“In 2015, we are ... moving forward to reinvigorate Congress and challenge delegates to break boundaries and create connections”*.

In response to their decision, the RACP has been inundated with letters from its members and other medical practitioners expressing shock and condemnation. The controversy has been extensively reported in the media, and has been a public relations disaster for the RACP. Dr Syme labelled the decision as “cowardly” and “insulting”, and an attempt to stifle debate. *“The outcome is an act of academic censorship of the worst kind – they did not know the content of my address”*.

The speech that Dr Syme was not allowed to deliver at the conference has now been published in mainstream media and, ironically, has reached a far greater audience than if it had just been presented at the RACP Conference. We have put a link to the full speech on our DWDnsw website.

Dr Syme’s speech ends with the following lines:

*“Some people listening to me may think I am violently opposed to palliative care. Not so.*

*I support the open and frank communication between dying patient and doctor, of supporting your patient to go as far with their life as possible, and encouraging the acceptance of the reality of dying, the maximal relief of pain and suffering, giving them a sense of control over the end of their lives, respect for patient autonomy and encouraging dialogue between dying patient and family with the important object of allowing them to say goodbye – all good palliative principles.*

*But I do not accept the rigid imposition of a particular model of care, and a limited choice at the end of life which condemns some people to die in a way that is anathema to them, in order to satisfy the moral view of their doctor.”*



## Elderly Couple End Their Lives

A Sunshine Coast couple, Terry and Jenny Law, both 74, were found dead in their unit on 15 May, after the alarm was raised by long-time friend. The couple were found sitting side-by-side in recliner lounge chairs, hand in hand, heads on each other’s shoulders.

A friend of the couple had received a letter from Mrs Law after they had died. It explained their decision to take a lethal substance that would enable them to die on their own terms. It described her husband’s terminal cancer diagnosis, her own chronic back complaint, and the extreme pain that they both suffered.

The death of the Laws came as a huge shock to their friend who received the letter and to the whole community in which they were loved and respected. They were known for their dedication to each other. Dallas Furner, who knew Terry Law well, said, *“Just knowing how close knit him and Jenny were, I can understand why they did what they did.”*

A response to their death published in *The Sunshine Coast Daily* stated, *“The real tragedy is the number of terminally ill who feel compelled to resort to a violent, lonely death because there is no option. The agony in these situations is not limited to the individual. Consider the family and friends who had no opportunity to say goodbye. These events are happening in your community more often than you might think.”*

## Police Investigate Death



Dorothy Hookey with her husband Graham

Victorian Police are preparing a report into the death of 86 year old Dorothy Hookey, who took a lethal substance to end her life in November, 2014. Mrs Hookey, who suffered severe arthritic pain, left a note explaining that it was solely her decision, and affirming that she took the substance unassisted. In an interview with *Fairfax Media*, her husband, Graham, said that she had deliberately chosen to take her life alone, without telling anybody about the timing, because she feared implicating them.

Nevertheless, because Graham and their adult children were in the house at the time (albeit asleep in other rooms) the family were subjected to a full-scale Police investigation involving extensive forensic examination and a stream of police visits and interrogations over several months. The Police took the family's computer and Ipad, and tried to find any books that Mrs Hookey might have used to plan her death. *"To me, it's just such a shocking waste of police resources,"* said Graham Hookey. He is also angry about the cruel state of the law which compels someone to take such a measure completely alone and without being able to tell their loved ones.

When asked about the Hookey family, Premier Daniel Andrews said he hoped Victorian police and others in the community would be *"appropriately sensitive to anyone suffering a terminal illness and those who have provided care to them"*.

Dr Rodney Syme said after years of watching police investigations into various suicides and being interviewed himself over some deaths, it was unlikely the Police would prosecute anybody over Mrs Hookey's death. *"You have to actually do something to aid and abet and there has to be proof of it,"* he said. *"In the absence of any evidence, it's almost impossible to prosecute."*

This case prompted Victorian Sex Party MP, Fiona Patten, to say, *"It is now time for the community and politicians to once and for all have a wide debate about voluntary euthanasia and agree that everyone has the right to a dignified death."*

## Victorian Parliamentary Inquiry

Last month the Victorian Greens sought to put voluntary assisted dying back on the political agenda. Colleen Hartland, MLC, presented a motion calling for Victoria's Attorney-General to refer the matter to the *Victorian Law Reform Commission*. It was hoped that, as a first step, the commission would conduct an inquiry, canvass public views, and report back to Parliament with a range of options. The Greens' motion was never voted on, as it became clear that there was not enough support for the Bill to pass.

The debate prompted Gavin Jennings (Labor), Leader of the Upper House, to move a separate Bill launching an inquiry into the broader topics of end of life issues. This motion was passed, 29 votes to 9.

*The Upper House Standing Committee on Legal and Social Issues* will conduct the Inquiry. It will comprise three Labor MPs, three Coalition MPs, and one representative each from the Sex Party and the Greens and will look at three key areas:

- How current medical practices and palliative care can assist a person manage their end of life
- How this issue is managed in other Australian and international jurisdictions
- Potential changes to our legislative framework.

The Inquiry will provide a good opportunity to highlight some of the problems associated with current legislation, and to further engage the public in discussion on end of life choices. Submissions to the Inquiry are open until 31 July, 2015. The Committee is due to report back to the parliament by the end of May, 2016.

## DWD Ambassador Kirner Dies

The Committee of DWDnsw were saddened by the death of Former Victorian Premier, Joan Kirner AC.



Joan died on 2 June, aged 76, after a two-year battle with oesophageal cancer.

Dying with Dignity is very proud to have had Joan Kirner as one of our "Ambassadors for Law Reform" and we greatly appreciated her support for the cause of voluntary assisted dying.

## Vale Margaret Sargent



Dr Margaret Sargent, died on 13 March. In a career spanning over 50 years, Margaret was a clinical psychologist, sociologist, activist and author.

Margaret joined DWDnsw in 2007, when her daughter, Sociologist Dr Wendy Sargent, was diagnosed with ovarian cancer. Wendy died in 2011, aged 56. In her book *Older and Bolder: Challenges of Ageing*, Margaret Sargent urged readers to seize control over the dying process. Sadly, the final months of her life were not comfortable and, as a final act of defiance and dissent, she refused all food and medication in the last few weeks of her life.

## 20 Years Since VAD in Australia

We have just marked the 20 year anniversary of the passing of the Northern Territory's *Rights of the Terminally Ill Act* on May 25, 1995. The Northern Territory of Australia became the first legislature in the world to pass a law for voluntary euthanasia.

The Bill was presented to Parliament under the stewardship of the Chief Minister of the Northern Territory, Marshall Perron, a member of the Country Liberal Party. The laws came into effect on July 1st, 1996. Four Australians, all dying from cancer, legally received medical help to die, before the Federal Parliament overturned the Act in March 1997.



Marshall Perron, 2015, still campaigning for voluntary assisted dying laws in Australia

## Elderly Suicide Under-Reported

The following is an edited version of an online article published in "DPS News" on the website for seniors: [www.agedcareguide.com.au](http://www.agedcareguide.com.au).

Three Australians aged 75 and older take their own lives every week, according to *Australian Bureau of Statistics* (ABS) data. If the base age is reduced

to 70 years, then the number is closer to four per week. Both the ABS and most coroners agree that the figures are under-reported.

In the 10 years to 2004, almost 1,500 Australians aged 75 years and older killed themselves, mostly by hanging. Australia's rapidly ageing population means the numbers of such suicides can be expected to increase.

According to Marshall Perron, pictured left, the fact that a doctor cannot lawfully assist them die by prescribing appropriate drugs, many of these deaths are unnecessarily premature, lonely and violent. "*Premature because the individual has to act while they have the physical and mental capacity. Lonely because the individual is aware that assisting a suicide is an offence and they do not want to implicate family or friends. Violent because they must use whatever means to die they can access.*" Perron says there is a high level of interest in learning how to die peacefully and importing illegal substances to achieve that aim.

According to Dr Rodney Syme "*The real tragedy is that elderly people who wish to end their suffering – both physical and existential – can't even discuss their intentions with their doctor because the doctor will likely try to dissuade them as he or she cannot 'help' them.*" Syme says that, without information or access to appropriate drugs, elderly people invariably suicide violently and alone, aggravating the trauma experienced by loved ones.

Fear of loved ones being implicated in unlawful acts also prompts people to plan their suicide secretly, without consultation or goodbyes. Examples of terminally ill people scheming to be alone to suicide without interference are common.

Marshall Perron has observed that, "*with rare exception, politicians avoid the issue whenever they can...Anxious to avoid antagonising a religious minority in their electorate, the easy thing to do is nothing. They try to ignore the subject in the hope it will go away...*

*.....The community is not asking politicians to lead on this issue, they are asking them to catch up..... Apart from religious fundamentalists, politicians are the only group who cannot seem to grasp the shift in community attitudes brought on by a rejection of pointless protracted suffering when death is inevitable."*

\* \* \*

See personal story "My Dad" by Tracey Walker on page 16.

# Disobedience: A Path to Clarity

## By Dr Rodney Syme

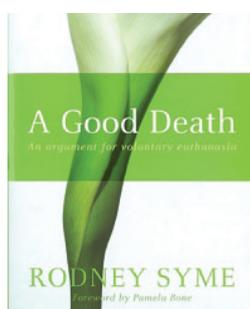
Following is an extract from an Opinion Piece “Disobedience: A Path to Clarity in End-of-Life Law” published in *The Brisbane Times* on 13 May, 2015. The full article is on our website.

Doctors have an ethical duty to relieve suffering, and to respect the autonomy of their patients. *The Medical Treatment Act 1988* says it is desirable that dying patients receive maximum relief of pain and suffering. So what does a doctor do when a person with intolerable and unrelievable suffering asks for assistance to die to relieve that suffering?

*The Crimes Act* says it is murder to intentionally end a life, even if a person is dying, even if only by a few hours. It is manslaughter if one can foresee that an action will cause or hasten death, and still take that action, and there is a further relevant offence of inciting, or aiding and abetting suicide. A doctor treating people at the end of life can come into potential, and actual, conflict with all these laws, which carry substantial penalties.

I have, for reasons of conscience and perverse nature, been challenging the law surrounding end-of-life decisions and actions for nearly 20 years.

In 1996 I first became aware of the practice of terminal sedation, also known as deep continuous sedation, whereby dying persons, in palliative care, were put slowly but progressively into a coma, without the provision of hydration, and maintained in that state until their clearly foreseen death. It took four years, and three deaths influenced by terminal sedation, managed by me and reported to the Coroner, before he confirmed that such deaths were not reportable.



In 2005 I gave advice and medication to Steve Guest, who was dying of oesophageal cancer. He took this medication to end his suffering. In 2008, my book, *A Good Death*, described my involvement with 20 of my patients and of my assistance in their

deaths, including that of Steve Guest. Two police interviews followed, but no action.

I finally acknowledged a year ago that I had given Nembutal to Steve, but also argued that my intention was to palliate him by giving him control over the end of his life and improve his quality of life. There is ample evidence that it did so. A further police interview followed,

but no prosecution, on the grounds that “*there was insufficient evidence*”. Since then, I have provided advice and medication to another 10 people, including Peter Short. Brave Peter did not take this medication, dying well in palliative care. Nevertheless, it provided him with powerful palliation. His medication has rolled over to Ray Godbold.

*The Office of Public Prosecutions* is between a rock and a hard place. It regularly prosecutes laypeople, who are involved in the deaths of suffering relatives, regrettably because they felt they had no alternative. Our judges show their dissent by regularly finding no reason for punishment in these cases.

As a doctor, I find an absence of clear end-of-life law has a profound effect on doctors, their patients and their families. I grieve that this status quo exists despite clear logic for change. Such a status may need a shove for it to change – that is what I am hoping to do. Sometimes non-violent civil disobedience is that shove.

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## International News

### Sir Terry Pratchett Dies

Fantasy author and campaigner for assisted dying, Sir Terry Pratchett, died on 12 March 2015, aged 66. Larry Finlay, of Pratchett’s publishing company, *Transworld*, said he did not take his own life and “*The world has lost one of its brightest, sharpest minds,*” said. Sir Terry wrote more than 70 books over his lengthy career.

Pratchett was first diagnosed with Alzheimers in 2007, but continued writing, completing his final book last summer. Pratchett faced his Alzheimers disease, which he called “*an embuggerance*”, publicly and bravely.

In 2011 Pratchett explored the issue of voluntary assisted dying in a BBC documentary, “*Choosing To Die*”. The programme provided an insight into the issue of euthanasia, with Pratchett speaking to a number of people who had chosen to end their lives. It was especially poignant in light of his own diagnosis, with Pratchett considering whether he himself would want to end his life in this manner. In the documentary,

Pratchett travelled to Switzerland with Peter Smedley, suffering from Motor Neurone Disease, who had made the decision to die at a *Dignitas* clinic. During the final scene of the film, Pratchett witnesses Smedley’s death, after taking a lethal dose of Nembutal. The controversial programme

made an important contribution to the ongoing debate over assisted dying. Describing his reasons for making the documentary, Pratchett said 'it should be possible for someone stricken with a serious and ultimately fatal illness to choose to die peacefully with medical help, rather than suffer'.



Terry Pratchett with Peter and Christine Smedley in a scene from the documentary "Choosing to Die"

A link to the "Choosing to Die" video is available on our DWDnsw website, as is a link to Pratchett's excellent 2010 lecture, *Shaking Hands With Death*, which was the 34th *Richard Dimpleby Lecture*, hosted by *The Royal College of Physicians*.

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## California USA

### California Senate Approves End of Life Option Act

On 4 June the Californian Senate passed Bill 128, also known as the *End of Life Option Act*, with a 23-14 vote. It will now go before the State Assembly, and if passed, will allow terminally ill adults with six months or less to live, the right to a medically assisted death. The Bill is closely modelled on the Oregon *Death with Dignity Act 1997*.



Debbie Ziegler, Brittany Maynard's mother, broke down as she appeared at California's state legislature to urge assisted death laws.

Debate in California on end-of-life issues was renewed after Brittany Maynard moved to Oregon from California in 2014 so that she could have an assisted death under that state's aid-in-dying law. The Vice President of *Death with Dignity National Center*, George Eighmey, said, "Our testimony on

*the 17 years of flawless implementation of Oregon's law not only refuted the opponents' unfounded allegations, but convinced many senators that having a similar California law would provide their constituents with the full range of end-of-life options."*

State Senator, Bill Monning, co-author of the Bill said "We don't seek to change church doctrine. We don't seek to enforce this on anybody, only a voluntary patient, working with doctors, are engaged, voluntarily."

### Californian Doctors Drop Opposition to VAD

On May 20, the California Medical Association (CMA) announced that it would no longer oppose voluntary assisted dying (VAD) legislation. It is the first Medical Association in America to do so.

This announcement came after 30 years of opposition to VAD. CMA officials said they were motivated by the desire to preserve the doctor-patient relationship, and made the decision after extensive consultations with lawmakers. CMA President, Luther Cobb, said in a statement, "As physicians, we want to provide the best care possible for our patients ... However, despite the remarkable medical breakthroughs we've made and the world-class hospice or palliative care we can provide, it isn't always enough."

Polls repeatedly show that the majority of Californians are in favour of such a law

### Californian Court Case

At the same time as the Parliament is addressing the issue of VAD in California, the advocacy group *Compassion and Choices* has filed a suit in the California Superior Court on behalf of three people with terminal or advanced diseases.

The suit argues that California's Penal Code S.401 (which prohibits medical aid in dying for a mentally competent, terminally ill adult) is unlawful and unconstitutional.

The suit also asserts that VAD is a more peaceful alternative to palliative sedation, which involves medicating the patient into a coma and withholding nutrition and fluids until the patient dies.

The lead plaintiff is 46 years old single mother, Christy O'Donnell. Despite receiving chemotherapy every week for the last nine months, O'Donnell's doctors have told her that she is likely to die

painfully within the next few months from lung cancer that has spread to her brain, spine, ribs and liver. O'Donnell, pictured, is fighting to stay alive until her daughter's 21st birthday in June and for the law to allow her to die the way she wants.



In a video released by *Compassion and Choices*, O'Donnell said, *"The most likely way that I'm going to die with the lung cancer is that my left lung will fill with fluid, I'll start drowning in my own fluid... I spend an inordinate amount of time being afraid of the pain that I'm going to endure. All of that time that my mind spends thinking about that, I am not living."*

The second patient plaintiff, Elizabeth Wallner, has colon cancer that has spread to her liver and lungs. She has had 18 rounds of chemotherapy, four surgeries to remove parts of her liver and colon, radiation, radio-ablation, and other treatments. Elizabeth and her family, including her 19-year-old son and her Catholic father, support her end-of-life wishes, including the option of aid in dying.

The third plaintiff is Wolf Breiman, diagnosed six years ago with multiple myeloma, an incurable cancer of the white blood cells.

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## Assisted Dying Legal in Colombia (South America)

Voluntary assisted dying has been in legal limbo in Colombia for 18 years. In 1997 Colombia's Constitutional Court ruled *"no person can be held criminally responsible for taking the life of a terminally ill patient who has given clear authorization to do so"*. However, Colombian doctors still feared prosecution, due to a separate law that made mercy killings punishable by up to three years' imprisonment. VAD remained taboo in this predominantly Catholic country

In March this year, the Constitutional Court acted to strengthen the legality of voluntary assisted dying, and ordered the Health Ministry to issue regulatory guidelines within 30 days. The death of Brittany Maynard in Oregon and the ruling of the Canadian Supreme Court were seen as catalysts for the Constitutional Court's action.

The Health Ministry's guidelines, published on 20 April included very strict safeguards. This step makes Colombia the first South American country to legalise voluntary assisted dying.

Carmenza Ochoa, director of the *Foundation for the Right to Die with Dignity* (DMD), has hailed the Health Ministry's guideline as an important step for Colombia. In response to concerns that the laws may result in vulnerable people being euthanised against their will, Ochoa said, *"If you kill someone against their will, that is not euthanasia; that is murder, and this law does not change that fundamental fact."*

Oschoa's response to The Columbian Catholic Church's letter of protest to the Health Ministry was, *"If others regard life as sacred, and are opposed to euthanasia, then we respect that. No one is going to push euthanasia on them. But for those who want euthanasia, their rights should also be respected."*

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## VAD Laws Safe in Montana and Vermont USA

In two American states where voluntary assisted dying has been legalised, recent attempts to overturn existing laws have failed.

In the 2009 *Baxter v. Montana* decision, the High Court of Montana ruled that doctors could use a patient's request for the lethal medication as a defence against any criminal charges. Since then, the Legislature has struggled to clarify whether the practice is legal or illegal. Five years of public debates and legal challenges later, the original *Baxter v. Montana* ruling stands. Two bills intended to overturn end-of-life options were recently defeated. The majority of Montanans and their elected representatives support the existing law allowing assisted death.

Opponents also failed in their efforts to repeal Vermont's aid-in-dying law, which was passed two years ago. Two separate amendments that would have dismantled the law have been defeated. As further affirmation, the Vermont Senate gave final legislative approval to S.108, a bill that supports the state's 2013 law.

Barbara Coombs Lee, President of *Compassion and Choices*, decried these results as *"significant victories"*, as she asserts that *"Aid in dying will become harder to repeal as the years go by."* Nevertheless, Coombs Lee warns that we must remain poised to protect these laws that so many people have fought for years to establish.

## New Zealand: High Court Challenge for the Right to Die

Lecretia Seales, lawyer and policy advisor at the *New Zealand Law Commission*, was diagnosed with a terminal brain cancer in 2011. Seales mounted a challenge in the NZ High Court, seeking the right for her doctor to help her die without risking criminal prosecution.

Under the *New Zealand Crimes Act 1961*, those found guilty of aiding or abetting suicide may face up to 14 years' imprisonment. The Crown's position was that there is a clear, total ban on helping someone to die. Seales' legal team argued that a total ban is counter to the *New Zealand Bill of Rights*, which protects the right to not be subjected to cruel treatment. (The existence of a Bill of Rights in Canada and South Africa were considered pivotal to Court rulings in favour of VAD in those two countries earlier this year.)

Seales began the court proceedings in March, when it was expected she might live between three and 18 months. However, by the time the case was heard in late May, she was gravely ill, and sadly died on 5 June, aged 42.

The High Court Judge hearing the case, Justice David Collins, informed Ms Seales' family of his decision on 2 June, just three days before she died. Sadly, Seales would not get her dying wish. Collins ruled that under current law, it would be illegal for her GP to provide a fatal drug to help her die, and that doing so would risk prosecution for assisting suicide, murder or manslaughter. *"The complex legal, philosophical, moral and clinical issues raised by Ms Seales' proceedings can only be addressed by parliament passing legislation to amend the effect of the Crimes Act,"* Justice Collins said.



Lecretia Seales, during healthier times

NZ Labour MP, Iain Lees-Galloway, said, *"I thought Lecretia was incredibly brave and the fact that she continued her fight literally right up to the end was amazing ..... I really hope that the effort that she put in makes a difference."* Both Labour and National MPs in New Zealand are now talking about moving forward with action on legalising voluntary assisted dying.

## South African Court Ruling Allows VAD

For the first time in South Africa, a High Court judge has ruled that a terminally ill man has the right to access medical help to end his life. Judge Hans Fabricius ruled that Robin Stransham-Ford, pictured, could access voluntary assisted dying with no legal or professional consequences for the doctor who will participate.



Stransham-Ford, aged 65, had prostate cancer, which left him in constant pain. The medication used to manage his pain meant that he was sedated most of the time. He died on 30 April, just hours before the Pretoria High Court ruled in favour of his application filed by *DignitySA*.

In 1998, President Nelson Mandela asked the *Legal Resource Centre* (LRC) to research *"assisted suicide and the artificial preservation of life"*. The commission did extensive work, found in favour of assisted dying and wrote a draft Bill. It was handed to the Health Minister in 1999, but was never presented to Parliament. In his 60-page judgment in Stransham-Ford's case, Judge Fabricius backed the right-to-die ruling, by referring to the 1998 draft law on the issue.

Judge Fabricius said that the law should be based on the 1998 LRC report on assisted dying, and viewed through the lens of *The Bill of Rights*. The state argued that the right to life meant VAD was illegal and unconstitutional. Judge Fabricius quoted the ruling of former Justice, Kate O'Regan, that the right to life is not separate from the right to dignity. This meant the constitutional right to life could not be used to deny Stransham-Ford's request that he be allowed a dignified death. Judge Fabricius said that *"rather than religious or moral ideas, the constitution should inform the public's view."*

Stransham-Ford died before receiving the ruling, but Judge Fabricius refused to withdraw his order and said an appeal must decide whether his judgment was moot. It is anticipated that several parties, including *Doctors for Life*, will appeal the decision.

## Irish Case Promotes Debate

An Irish judge has acquitted a Dublin woman, Gail O'Rorke, who was charged with attempting to assist the suicide of her friend, Bernadette Forde. It was alleged that O'Rorke had tried to help Forde make arrangements to travel to *Dignitas* in Switzerland, and after the authorities had prevented this, of helping her to procure lethal medication.

Forde, who had suffered with primary progressive multiple sclerosis, ended her life by taking medication (Nembutal) purchased on the internet. O'Rorke was not present when Forde took the medication, but the prosecution alleged that she had helped to procure it by making a money transfer to Mexico.

Judge McCartan ruled that there was insufficient evidence to prosecute Ms O'Rorke, and directed the jury to find her not guilty on both charges. He said "*justice has been done*".



Tom Curran, Marie Fleming and their son, Simon Fleming outside the High Court in 2013

Tom Curran, the partner of campaigner Marie Fleming, spoke out to ask why O'Rorke was charged with providing assistance to Forde, when it would have been an act of compassion for her friend. Curran referred back to Fleming's constitutional challenge in 2013, where the High Court stated that it believed the Irish Director of Public Prosecutions (DPP) would use the same guidelines issued by the UK DPP in deciding whether to prosecute - that if a person was carrying out the wishes of a rational adult, with an incurable illness, who was making an informed decision to die, and was acting out of compassion for that person, it is unlikely they would be prosecuted.

According to Tom Curran "*Most of us are shocked and revolted by murder, suicide and genocide, but when someone we know and love cries out, with justification, for help to die, who among us dares to respond?*"

Curran has been working with four barristers on a draft Right-to-Die bill since his partner, Marie Fleming, lost her Supreme Court appeal in April 2013. Fleming, who also had multiple sclerosis, died eight months later, aged 59. Curran's bill is based upon Oregon's *Death With Dignity Act* and will be introduced into the Dáil (Lower House Irish Parliament) by Independent MP, John Halligan.

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## Scotland Rejects VAD Bill

Veteran Independent Scottish MP, Margo MacDonald, fought for the legalisation of voluntary assisted dying for many years. Her *End of Life (Scotland) Assistance Bill* was voted down by the Scottish Parliament in 2010. Following a long battle with Parkinson's disease, MacDonald died last year. The Leader of the Scottish Greens, Patrick Harvie, gave his commitment to MacDonald that he would present her second bill to a future parliament.

Harvie presented the Bill on 27 May, this year, but, disappointingly, the Scottish Parliament voted it down again. The Bill was defeated, 86 opposed, with only 36 MPs in favour. There is substantial resistance to law reform on this issue, with the Church strongly urging MPs to vote against it.

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## World Federation

On 1 April 2015 the new global organisation called the *World Federation of Right to Die Societies* was formally established in Geneva. This non-profit organisation replaces the New York corporation of the same name, founded in 1980. The Federation is "*independent of any government, political party, ideological or religious group.*"

The Federation's website [www.worldrtd.net](http://www.worldrtd.net) includes news of achievements in the campaign for voluntary assisted dying from around the world. The next biennial meeting of the Federation will be in Amsterdam in May 2016.

**If you want the latest news between newsletters, there are news articles and editorials updated regularly on our Dying with Dignity NSW website: [www.dwdnsw.org.au](http://www.dwdnsw.org.au)**



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## “My Dad” by Tracey Walker

This is the story of my brave, sensitive and loving father. Russell Alfred Walker was born in Parramatta to a working class family. He was one of five children. During his young life he was hospitalised for long periods with asthma. Frequently debilitated by the illness, doctors told his parents that he would be lucky to see his teens. But he did.

My Grandmother used to sit next to Dad during his hospital stays, telling him to breathe. She also told him that he could do anything he wanted, if he really put his mind to it. Dad survived, and took grandma’s message to heart. He was determined to overcome the obstacles that had been placed before him. He was told he would never be able to play sport because of his asthma, so, stubbornly he played football and squash. He also became a keen surfer and swimmer.

Dad married at age 21, and had two daughters and a son. In February 2008, my daughter Ruby was born, and she was “*Poppy’s Little Princess*”. Sadly, it was in the same year that Dad was diagnosed with Parkinson’s Disease.



Russell Walker with his grandchildren

Dad noticed little things changing. For instance, it became difficult to comb his hair and to clean his teeth. When he walked he didn’t swing his right arm. When he was finally diagnosed, Dad was devastated.

He enrolled in a six-week *Catholic Adult Education Seminar*, and seemed to get some comfort from this. Always a fighter, Dad continued to be motivated to keep pushing himself physically and mentally. As other medical problems emerged, he rose to the challenge. In May 2014, he had a knee replacement, which gave him more mobility and made him feel much better. However, soon afterward the operation, he contracted Influenza A. This completely debilitated him, and he was unable to do even the smallest task.

Once again, determined to recover, Dad did everything he could to find an answer. He went to more doctors and lung specialists, had PET scans, MRIs and numerous blood tests. He completed a rehabilitation program for Parkinson’s Disease patients at Cavalry Hospital, and changed his medication (which unfortunately made him vomit and created a metallic taste in his mouth).

Everything my Dad loved to do: surfing, swimming, cooking, walking his granddaughter to school, had been taken away from him. He became totally debilitated, unable to do more than sit in a chair, for days and weeks at a time. Dad always had a fighting spirit, and was determined to overcome any obstacles that came his way, but now he was defeated. Once a very proud, energetic and brave man, he was now totally helpless and he hated it.

On Sunday 12th April 2015 my beautiful generous father hung himself in his bathroom. He was only 73 years old. Our hearts are broken and our lives will never be the same.

It was bad enough that my Dad had a progressive neurological illness and a range of other medical complications. Much worse than that was the terrible way that he ended his life.

Previously, I have never thought much about voluntary euthanasia. I now strongly believe that everyone should have the choice to die with dignity when they are hopelessly ill and suffering. I hope that one day there will be a change in the law, so that other people will not have to go through what Dad went through. No one should have to end their lives violently and alone.

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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