

Dying *with* Dignity



Tasmania (Inc)

FEBRUARY 2015

**We wish all our members and supporters
our very best wishes for 2015.**

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- **NEWS FROM OVERSEAS:** There have been many developments overseas with many positive signs for assisted dying legislation and a reason to be optimistic that the tide has turned.
- **COMMITTEE FOR 2014 - 2015 AND MEETINGS**

STOP PRESS: MAJOR CANADIAN SUPREME COURT DECISION IN FAVOUR OF ASSISTED DYING

On 6 February, in a unanimous decision of 9-0, the Canadian Supreme Court struck down as unconstitutional the nation's century-old law against assisted suicide. It found the absolute Criminal Code provision against aiding and abetting someone to commit suicide goes too far and deprives those suffering from grievous and irremediable medical conditions the right to life, liberty and security of the person as guaranteed under the Charter of Rights and Freedoms.

The court's ruling limits physician-assisted suicide to "a competent adult person who (1) clearly consents to the termination of life and (2) has a grievous and irremediable medical condition (including an illness, disease or disability) that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition."

President's Comment: There comes a time in any reform campaign when you know the tide has turned, and it's a matter of 'when', not 'if', the reform will be achieved. That time has now come for voluntary assisted dying (VAD) legislation. This Canadian decision is yet another sure sign adding to all the other developments reported on in this newsletter. We really can go into 2015 feeling very optimistic.

YOUR RIGHT TO CHOOSE

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PRESIDENT'S REPORT - JUNE - FEBRUARY

Sorry we haven't been in touch as much over the last few months. Other things have distracted me from the newsletter - including a hip replacement (fortunately very successful). There has been quite a bit of activity to report on, both by DwDTas and beyond.

My key message is that we can go into 2015 very optimistic about the future for improvements in all of the areas that contribute to dying with dignity - encouragement to talk about dying as a part of life, what it means to die well, the importance of more widespread palliative care, support for end of life planning through advance care directives and the need for law reform to allow a choice of assisted dying.

It may still be some time till the law changes and it may feel like "2 steps forward, 1 back" but we can take heart from the recent developments. Fear-mongering campaigns work - but only for a limited time. Their effectiveness diminishes as each new Bill is passed (or positive court decision is made) and more and more politicians reject the fear-mongering that has no basis in compassion or respect for others and no basis in facts, evidence or logical and reasonable assumptions and conclusions.

The most obvious positive signs in Australia and overseas are:

- There has been an increase in VAD laws and many more Bills. More politicians are making public their support and taking action to move Bills.
- More and more people are telling their stories publicly and showing the personal cost of what palliative care experts and bodies such as the AMA

make clear - palliative care cannot relieve all end of life suffering.

- The media is covering the issue more widely and (generally) more fairly, with respected journalists and commentators making their support known.
- More religious leaders and committed Christians are making their support known and arguing how consistent their views are with their Christian values, eg former Archbishop of Canterbury, Lord Carey, and Bishop Desmond Tutu.
- More doctors are expressing their support of VAD laws or at least accepting the fact that they are inevitable and each doctor should have the choice to act on their own conscience and values, eg Canadian Medical Association.
- There has been a significant increase in information and encouragement to talk about death and for everyone to express their end-of-life wishes in advance care directives and enduring guardianships/powers of attorney. As more people think about the issue and express their wishes, they find it increasingly hypocritical and untenable to be told we can express our wishes - but don't expect them to be met if we ask for assisted dying because someone else doesn't want us to have that choice.

Major activities by DwDTas since our last newsletter have included:

- The AGM held in July followed by an extremely interesting and challenging presentation by our guest speaker, Associate Professor Jane Tolman, on dementia and her approach which is that the best care will be a palliative approach from the time of diagnosis. Dr Tolman has offered to make a similar presentation in the NW and we will be trying to arrange that.

- Activities related to the Exposure Draft Medical Services (Dying with Dignity) Bill, moved in the Senate by Greens Senator Richard Di Natale. See more details below.
- Response to the consultation by the Department of Health and Human Services, on a draft policy framework, 'An Approach to Healthy Dying in Tasmania'.

We've continued our ongoing encouragement and support of end-of-life planning including presentations by Bill Godfrey and an approach to the Tasmanian Hospice and Palliative Care Association to collaborate more on this issue.

In the last newsletter we reported on the State Liberal election commitment to \$100,000 for a feasibility study into a stand-alone 10-bed hospice for Launceston. There was a major launch of the Northern Hospice and Palliative Care Foundation at a very well-attended cocktail party in Launceston on 14 November which I attended. The attendance showed how great the support is by those with influence in the community, including politicians and former politicians. This augurs well for the work and fund-raising of the Foundation for the hospice. The North of the State has been significantly worse off than the South since the closure of the Philip Oakden House hospice.

We have continued our monitoring of developments elsewhere and research to start our planning for another Tasmanian assisted dying Bill, even though this may not be till next year.

Life Membership for Allan Cameron AM: At our August meeting, there was strong and unanimous support for a Life Membership to be granted to Allan in recognition of his

long and active support and work for voluntary assisted dying choice. This has been as a member of the DwDTas Committee and in the community, including the Liberal Party. We know that Allan will continue to be a passionate advocate. Thank you very much Allan on behalf of all DwDTas members.

NEWS FROM AROUND AUSTRALIA

MEDIA: Every week there are numerous items in the media throughout the country related to voluntary assisted dying. The issue is well and truly alive even if we get none of that coverage in Tasmania. If you're interested, Dying with Dignity Victoria regularly summarises this news and you can access other news at <http://www.dwdv.org.au>. DwDNSW also provides up to date news on its website.

"DYING WELL": This is the title of a very welcome paper from the Grattan Institute by Hal Swerissen and Stephen Duckett (<http://grattan.edu.au/report/dying-well/>). They make important points including that 70% of Australians want to die at home yet only 14 % do so and that dying in Australia is more institutionalised than in most countries due to medical and community attitudes plus a lack of funds for formal, home-based care. They advocate three reforms we can all agree on: *"First, we need more public discussion about the limits of health care as death approaches, and what we want for the end of life. Second, we need to plan better to ensure that our preferences for the end of life are met. [A welcome shift from just being able to express them!] Third, services for those dying of chronic illness need to focus less on institutional care and more on people's wishes to die at*

home and in homelike settings. For more people to die at home, investment in community-based support is needed.”

NATIONAL: The major national news relates to the Senate Committee inquiry and report into the Exposure Draft Medical Services (Dying with Dignity) Bill moved by Greens Senator Richard Di Natale.

A submission by DwDTas was one of the 663 submissions received by the committee, with 173 published on their Parliament of Australia website. They also received over 4,700 pro forma submissions. If you would like a copy of our submission, please contact us.

The main points of our submission were:

- Background information on the 2013 Tasmanian Proposal and *Voluntary Assisted Dying Bill*. (The Di Natale Bill demonstrated absolutely no knowledge of these documents.)
- In-principle support for the intention of the Bill to meet a well-established need.
- Evidence that overseas assisted dying legislation is providing a compassionate and responsible option as part of overall end-of-life care.
- *The Medical Services (Dying with Dignity) Bill 2014* needs significant amendment before it meets the established standards for safe, responsible and effective voluntary assisted dying law reform suited to the Australian situation.

We also expressed the view that practical, relevant and effective legislation for voluntary assisted dying is only possible at State/Territory level. Whether the proposed legislation is within the Constitutional powers of the Australian Parliament or not, we argue that practical, relevant and effective legislation can only

be determined, implemented and administered at a State/Territory level.

We also provided a lot of information to Senator Lisa Singh and briefed her thoroughly on the issue. She was not a member of the Senate Committee but able to participate in the hearings (she was able to attend only one of the two days of hearings). She became virtually the only participant to ask questions to challenge some of the inaccuracies, misinformation and irrational fears that were as usual trotted out by religious and medical opponents. There were also some excellent submissions including ones by DwD groups, Doctors for VE Choice and Christians for VE Choice. Peter Short’s appearance at the hearings was an extremely moving and powerful submission for choice at the end of life.

On 10 November, the Senate Committee reported its findings. We were extremely disappointed that the report did nothing to correct the inaccuracies and misleading claims it received but welcome the key recommendations:

1. That Senator Di Natale should address the technical and other issues raised in evidence to the committee, and seek the advice of relevant experts before drafting the final Bill.
2. That if the Bill is introduced in the Senate, Party Leaders should allow Senators a conscience vote.

Since the Senate report, Senator Di Natale has started consultation with DwD groups through Your Last Right. Dr Rodney Syme and Margaret Sing worked on an initial proposal to members of YLR. Discussions are continuing to prepare an agreed model of legislation and identify differences of approach for meeting with Senator Di Natale and other supportive MPs.

VICTORIA: We reported in our last newsletter about the courageous campaign by Peter Short. Peter died on 29 December. The Good Weekend magazine (the Age and Sydney Morning Herald) on 23 January included an article which is well worth reading - <http://www.smh.com.au/good-weekend/final-project-peter-shorts-campaign-for-change-20150123-12ixs5.html>. Before he died, Peter's lobbying of Tony Abbott resulted in a call from him and a commitment that Coalition members would be given a free vote ('conscience' vote).

We also reported on Dr Rodney Syme's courageous action in publicly stating that he had given Nembutal to Steve Guest and the ongoing excellent coverage of the Age newspaper in support of VAD law reform. Rodney was subsequently interviewed by police and we understand that no action has been taken or is likely to be.

Despite these efforts, in the Victorian State election politicians and aspiring politicians - with few exceptions - continued to show how out of step they are with the community. The ABC's Vote Compass found 77% support for the proposition: "Terminally ill patients should be able to legally end their own lives with medical assistance".

A successful candidate in the Upper House, Ms Patten of the Sex Party has said her first order of business when parliament resumes on 10 February 10 would be pushing for action on voluntary euthanasia through the Victorian Law Reform Commission or a parliamentary inquiry.

SA: Another Bill is likely to be moved this year co-sponsored by a cross-Party group of backbenchers.

Sadly, one of the most active proponents of legislation in the SA Parliament, independent MP, Dr Bob Such, died from a brain tumour in October, aged 70.

WA: Another Bill is likely to be moved this year.

NSW: DWDNSW is setting up a "Pollies Register" in the lead-up to the NSW election on 28 March. It will be launched at a forum at Parliament House on 25 February titled "Voluntary Assisted Dying, Democracy and Politics". They continue to be very active, including through their regional groups.

QLD: As in Victoria, assisted dying legislation failed to get the support of either of the main Parties in the Queensland State election, despite the ABC's Vote Compass showing 76% support. The findings were based on almost **70,000** respondents for the proposition: "Terminally ill patients should be able to legally end their own lives with medical assistance". Almost half strongly agreed.

(<http://www.abc.net.au/news/2015-01-28/vote-compass-majority-of-queenslanders-in-support-of-euthanasia/6049750>)

NEWS FROM OVERSEAS

There are many positive developments in assisted dying law reform overseas, especially in the US and Canada.

CANADA

The advances in Canada, a country similar to Australia, have been most significant and have been building for many years, through events we've reported on before, including the first positive judgement in the Gloria Carter case, the 2011 report of the prestigious scientific organisation, the Royal Society of Canada, which presented overwhelming evidence, arguments and recommendations in favour of VAD law; and

the excellent 2012 Dying with Dignity Report of the Quebec Parliamentary Committee inquiry that resulted in the legislation passed in June 2014.

The End of Life Care Act 2014 was passed by an overwhelming vote of 94-22, with no abstentions. There was support from MPs in all Parties, including the strong support of senior MPs including the Liberal Party Premier, a former doctor. The provisions for assisted dying are similar to those in the Tasmanian 2013 Bill. A legal challenge is likely to occur.

Recent developments include:

1. There are now separate VAD Bills in the two houses of the national Parliament.
2. Unlike our AMA, the **Canadian Medical Association (CMA)** is leading the way in a responsible and professional approach, reflecting a shift in doctors' attitudes and the willingness of more and more doctors to openly support and advocate for VAD legislation:
 - In August 2013, it decided to take "a leadership role and conduct a dialogue with both the medical profession and the public on end-of-life care issues". This included a survey of its members and "public town hall meetings". (Detailed reports are available on the CMA website.)
 - The survey in mid-2014 of almost 5,000 CMA members showed:
 - 44.8% said they were in favour of legalizing physician-assisted death [ie prescription of drugs to be self-administered by the patient]
 - 36.3% said they felt euthanasia should be legalized [ie doctor-administered drugs]

- 26.7% said they would be likely or very likely to participate if physician-assisted death was legalized.

<https://www.cma.ca/En/Pages/Physician-perspective-on-end-of-life-issues-fully-aired.aspx>

- At the CMA Annual General Conference in August 2014, 91% voted in favour of allowing individual physicians to follow their conscience in deciding whether or not to provide assistance.
- A December 2014 article reported: "The nation's largest doctors' group [the Canadian Medical Association] is quietly preparing for possible changes in federal laws governing physician assisted death, as support among its own members for medical aid in dying grows". This has included consulting "with medical associations in jurisdictions around the world where euthanasia or assisted suicide is legal to devise possible protocols for Canada if the federal law is changed".
www.thestarphoenix.com/health/Doctors+quietly+prepare+assisted+dying/10672703/story.html

US

The major event this last year and the strongest impetus for law reform was the brave and very moving campaign and death of Brittany Maynard, a young terminally ill Californian woman who moved to Oregon to take advantage of their Death with Dignity Act. Brittany was 29 years old and, with incurable aggressive brain cancer, she was faced with very great suffering at the end. As she said in a post on 7 October 2014: "*After months of research, my family and I reached a heartbreaking conclusion:*

There is no treatment that would save my life, and the recommended treatments would have destroyed the time I had left. I considered passing away in hospice care at my San Francisco Bay-area home. But even with palliative medication, I could develop potentially morphine-resistant pain and suffer personality changes and verbal, cognitive and motor loss of virtually any kind. Because the rest of my body is young and healthy, I am likely to physically hang on for a long time even though cancer is eating my mind. I probably would have suffered in hospice care for weeks or even months. And my family would have had to watch that."

(<http://wtvr.com/2014/10/07/brittany-maynard-my-right-to-death-with-dignity-at-29/>)

Because assisted dying is not legal in California, Brittany moved to Oregon with her husband and family, and died early in November.

The momentum for change has grown because of the gross insensitivity of Catholic and other opponents of assisted dying laws who haven't displayed an atom of compassion, understanding or respect for Brittany or her family. The potential effect of her story and action is so great that, within days of her death, the Vatican's top bioethics official Monsignor Ignacio Carrasco de Paula, head of the Pontifical Academy for Life, came out against it, calling her action 'an absurdity'. Brittany's mother, Debbie Ziegler, responded angrily saying "the comments came as the family was grieving and were 'more than a slap in the face'."

Pressure and action for assisted dying legislation or legal decisions continues in more US States, in attempts to get similar laws to those in **Oregon** (1997) and **Washington** (2009) and the court decisions in **Montana** (2009) and **New Mexico**

(January 2014). In 2013, the assisted dying law passed in **Vermont** was a major milestone as the first one passed in the US without a referendum beforehand and the first one in an Eastern State.

Positive signs of change in the US include:

1. The number of Bills is growing and, despite setbacks, more are likely to be successful. According to an article on 20 January 2015: "Since October [2014], lawmakers have introduced right-to-die bills in **Washington, D.C.** [District of Columbia], and **Pennsylvania**. They have pledged to do so in 13 other states, according to Compassion & Choices, which supported [Brittany] Maynard's cause and helped publicize her story."
2. Another January article reported that action was occurring in even more States including **Maryland** where Senator Ronald N. Young is drafting a 'death with dignity' Bill "allowing the person to say, 'I'm in pain, I'm in sound mind, and I don't want to go on like this'".
3. In August there was a vote against a Bill in **New Hampshire** but a vote in favour of a Committee to study "end-of-life" decisions, including "the positive and negative effects of legislation in states that have enacted aid-in-dying laws".
4. In November 2014, Aid in Dying for the Terminally Ill Act passed the **New Jersey**, State Assembly 41 to 31. The Governor may use his veto power and refuse to sign the Act into law.
5. In December 2014, two **Colorado** State representatives announced that they would be introducing a Bill in the first session in 2015 and a **New York** State Senator announced his plans to introduce a Bill.
6. On 21 January 2015, Brittany Maynard's husband and mother stood with nine **California** lawmakers to announce

legislation that would allow physicians in that state to prescribe medications to hasten death for the terminally ill.

(<http://www.smh.com.au/world/renewed--efforts-to-get-a-righttodie-law-passed-in-california-20150122-12vzlv.html>)

7. As in Canada, a major shift is occurring in doctors' opinions. In December 2014, it was reported that in a survey of 21,000 US doctors, 54% supported 'aid in dying', an increase from 46% in 2010.

(<http://www.nbcnews.com/health/health-news/most-u-s-doctors-now-support-aid-dying-survey-n269691>)

UK

The situation in the UK is concerning. The focus has been on the Assisted Dying Bill moved and debated in the House of Lords in July 2014. It progressed further in the Parliamentary process than any other Bill when it passed the Second Reading stage and moved into a detailed debate on the different sections (Committee stage). The positive publicity included the support by the former Archbishop of Canterbury, Lord Carey, and Bishop Desmond Tutu.

Lord Carey revealed that he had dropped his long-standing opposition to the

legalisation of assisted dying and "warned that by opposing reform, the Church he led risks 'promoting anguish and pain, the very opposite of a Christian message of hope'. ... The former Archbishop said he no longer believed the law should 'force terminally-ill patients to an unbearable point'; saying the current situation risks 'undermining the principle of human concern which should lie at the heart of our society'."

The key strategy of opponents has now changed to making the law unworkable. The debate is bogged down with 175 proposed amendments on the Bill.

The worst one passed so far is the requirement for a court order before assisted dying can be provided. This will put an extremely stressful, time-consuming and costly burden on people with intolerable and unrelievable suffering, and put assisted dying effectively out of reach for many of them. It was clear from the debate that families would be able to intervene against an order being granted.
President's Comment: Having legal requirements as bad as this is worse than having no assisted dying law because it puts the chance of a reasonable law years behind.

COMMITTEE FOR 2014 - 2015

Margaret Sing (President)
Helen Brookfield (Treasurer)
Maureen Aiken
Trish Kershaw
Barbara Porter
Dr Helen Cutts (co-opted)

Bill Godfrey (Vice President)
Keith Anderson (Secretary)
Mike Harris
Hilde Nilsson
Noel Woodrow

Patron: Professor Colin Wendell-Smith AO

Next meeting: 11 February at 2pm at the Glenorchy Library. If you would like to come to a meeting and join the discussion, you would be very welcome. Meetings are scheduled on the second Wednesday of each month but we are not meeting every month at present so please contact us on the DwDTas number beforehand to check if the meeting is going ahead.