

# Dying *with* Dignity



Tasmania (Inc)

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## DECEMBER 2015 - SEASON'S GREETINGS TO ALL OUR MEMBERS

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### TASMANIAN SITUATION

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**Voluntary Assisted Dying Bill:** Progress is being made towards a new Voluntary Assisted Dying Bill but it was not moved this year as expected. We have continued to discuss the new Bill with the MPs and have proposed some minor amendments to the 2013 Bill. We expect that a new Bill will be ready early in the new year.

As Andrew Denton has said: *"We are fortunate. There is now enough knowledge and overseas experience for us to draw on to create a law that we know will work. Better, the opportunity is there for us to take the best of different approaches from overseas."* This is exactly the basis for the Tasmanian *Voluntary Assisted Dying Bill 2013* - and will be the basis of the next Bill.

There has been no lessening of the commitment to a new Bill by former Premier, Lara Giddings, now Labor MP for Franklin, or Cassy O'Connor, now Leader of the Greens, who will co-sponsor the Bill now that Nick McKim has moved to the Senate in the Federal Parliament. We agree with them that a priority is gaining Liberal support and other approaches to demonstrate the facts and evidence about how well legislation is working overseas and can do here. This includes the possibility of a proposal to the Tasmanian Law Reform Institute to provide an objective, academic view and advice on a new Bill and other law reform issues.

We expect other developments in 2016 to increase the chances of the next Tasmanian Bill. The new Canadian legislation will be settled and is likely to mirror the Canadian Supreme Court decision which supported an option which was very similar to the Tasmanian *Voluntary Assisted Dying Bill 2013*. We also hope the report of the Victorian inquiry into end of life choices at the end of May 2016 will find in favour of voluntary assisted dying law reform. (See more below)

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### **Proposed new Bill to clarify end of life law:**

Catholic Labor MP, Madeleine Ogilvie, who is opposed to voluntary assisted dying choice, has proposed a new Bill, "Dying with Care and Consent to Medical Treatment", based on the 1995 SA Consent to Medical Treatment law. We support the aim of clarifying the current law on end of life decisions, including protection of advance care directives, which. But contrary to Ms Ogilvie's claim, her Bill is not a "compromise" or an alternative to voluntary assisted dying legislation. It doesn't tackle any of the problems of the status quo and the reasons we need a legal assisted dying choice for patients and doctors. It does nothing for the people with intolerable suffering that cannot be relieved by current methods. It does nothing to give them, and their doctors, the choice to relieve that suffering through a peaceful and dignified death.

Debate on Ms Ogilvie's Bill will provide better information about existing practices, including action by doctors to relieve suffering that hasten patients' deaths. We accept that there must be legal certainty to protect these compassionate practices. The limitations of those practices will also be acknowledged so that it's clear why some patients and doctors need and want the additional legal option of voluntary assisted dying. When the new Voluntary Assisted Dying Bill comes up for debate, MPs can then focus on the reality of the people whose intolerable suffering cannot be relieved at present despite the best efforts of our doctors and palliative care services.

We will provide more information in the next newsletter when we have done a detailed analysis of the draft Bill. On first reading, we have some concerns.

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### **EXCITING TIMES AND GREAT PROGRESS OVERSEAS AND IN AUSTRALIA**

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#### **Overseas - California and Canada:**

Overseas, recent developments show great progress towards the acceptance of voluntary assisted dying law by politicians who are well informed and respond with compassion and respect to the needs of people with intolerable suffering. In October, California achieved its new legislation and, in Canada, the election of the Trudeau Liberal Government greatly increased the chances of new legislation in that country in line with the February 2015 unanimous decision of the Canadian Supreme Court.

**Australia:** Andrew Denton's advocacy and evidence to the Victorian inquiry into end of life choices are providing high quality information supporting voluntary assisted dying law reform.

**CALIFORNIA:** In October, California became the 5<sup>th</sup> US State and the 11<sup>th</sup> jurisdiction to get legal voluntary assisted dying. The Californian *End of Life Option Act* is a major step forward for a number of reasons. It was signed into law by the Catholic Governor, Jerry Brown, who chose to sign it rather than use his power of veto despite heavy lobbying to do so. When signing it, he went to the heart of the issue and showed his empathy and respect for others, as well as his knowledge and understanding of the issue: *"The crux of the matter is whether the state of California should continue to make it a crime for a dying person to end his life no matter how great his pain and suffering" and "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."*

His views are supported by other Catholic views. Los Angeles Times columnist Jerry Lopez quoted from Dan Maguire, a Jesuit priest who now teaches moral theology at Marquette University, a Jesuit school: "For almost 50 years a number of Catholic theologians have taught that for the terminally ill, ending life may, at times, be the best that life offers. In some circumstances, death may be the best remaining friend and it is reasonable and moral to accelerate the dying process."

The law will provide virtually the same legal assisted dying option as that available in other US States, Oregon, Washington, Vermont and Montana. In the debate it was made very clear that all the credible evidence is that these laws are working well.

The success came after numerous previous unsuccessful attempts from as far back as 1992 and more recently in 2005 and 2007. A big factor in the success of this latest attempt was the impact of the Brittany Maynard story. Brittany was a 29 year-old Californian with an incurable brain tumour, who was forced to move to Oregon to access the assisted dying option she wanted. She died in November 2014 and her husband and family has advocated strongly for Californian assisted dying legislation.

California is by far the most populous US State with a population of approximately 38 million. The expectation is that more States will now follow its lead.

**CANADA:** The chances of Canadian voluntary assisted dying legislation - in keeping with the Canadian Supreme Court's decision earlier this year - increased significantly with the election in October 2015 of the Trudeau Liberal Party Government.

The Liberal Party voted in favour of legalising assisted dying at its national convention in February 2014. The new Prime Minister, Justin Trudeau, has spoken in favour of voluntary assisted dying (VAD) and talked about the experience of the death of his father, Pierre, and his wish for a dignified death.

We don't yet know the details of the Canadian legislation but the February unanimous judgement (9 - 0) of the Canadian Supreme Court, supported an option very similar to the last Tasmanian Bill: "physician-assisted death for 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".

The last government was slow to act and the panel they appointed to advise them was widely viewed as anti-assisted dying. On 14 November, the new Attorney General speeded things up by changing the mandate for the panel - they are no longer required to develop legislative options - and extended their deadline for reporting by only a month to 15 December.

The other significant factor in Canada is the principles-based, well-informed and fair policies of the Canadian Medical Association. We have put on our website a paper setting out why the CMA's policy and action provide such a good example for the Australian Medical Association to follow in its current review of its policy. Contact us for a copy or you can download it at <http://dwdtas.org.au/wp-content/uploads/2015/11/Canadian-Medical-Assoc-good-practice-Final-23Nov15.pdf>.

**ANDREW DENTON:** Since 29 October, Andrew Denton has been presenting his compassionate, humane and well-informed support for voluntary assisted dying law reform. This follows his 8 month extensive review which included speaking to many Australians (including Tasmanians) and people with the greatest experience of assisted dying laws, those in Oregon, the Netherlands and Belgium.

What he is saying is what DwDTas and colleague bodies, supportive MPs and other supporters have been saying but this is the first time a respected public identity in Australia has articulated so clearly the arguments and high quality information, underpinned by great compassion and humanity - and passion.

On Thursday 29 October in Melbourne, he presented the Di Gribble Argument, titled 'Watching my father die was the most shocking experience of my life.' The text is available at on the Wheeler Centre website (<http://www.wheelercentre.com/>). If you want a copy please contact us.

He reports the hundreds of hours of research he did talking to many, many people on both sides of the debate and then checking the claims. His starting point was an anti-euthanasia convention in Adelaide where he listened to all the accusations and claims of abuse, safeguards not working, slippery slope, babies being killed, etc etc. He then investigated every claim and found **none** of them were accurate - *"What I found was almost the exact opposite of what I'd been told: Long-running systems, based on years of open research and debate, with multiple safeguards, and overwhelming acknowledgement that they work, from across the spectrum – the public, medical bodies, and political parties of every hue".*

*And "I also found zero evidence within the system of the elderly and disabled being abused". He acknowledges how good our palliative care services can be BUT "the latest figures from Wollongong University's Health Services Unit, which collects data from 106 Palliative Care units across Australia, show that **one fifth of those in the last 24 hour of life died in moderate to severe pain despite the best efforts of palliative care**" and "for many people who are dying, their suffering will only end with their death because the pain is beyond treatment".*

In this situation people make *"rational and persistent requests for a hastened death"* but *"the most [palliative care services] will do for you, if you're that person begging for help, is what's called terminal sedation, where they slowly put you into an induced coma until you die". "Of all the things I learnt over the last 8 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. 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."*

Another major point made by Andrew is about the failure of the AMA to engage in the issue as it should. *"I have spoken with people all over the world and on all sides of*

*the debate, only one group has declined to be interviewed: The AMA.”*

All of these issues have been taken up and explored further in the media, including on Q&A, and there will be in-depth coverage in a series of podcasts. The first of a series of Andrew’s interviews, ‘Better off dead’, has been released and others will be released in the new year. The first podcast was run on the ABC Earshot program on 18 November and is also available at <http://www.wheelercentre.com/broadcasts/podcasts/better-off-dead>. It is a powerful, moving and distressing interview by Andrew with Liz Le Noble who's dying and wants to avoid pain and suffering at the end. It reveals the way her suffering is not only from the medical condition but from the lack of control, the insensitivity of her doctor about her needs, the barriers to choice, the impact on her son and family, and the way that having an option (through online purchase of Nembutal) has enabled her to live longer and not resort to terrible ways to end it.

Andrew has also been extremely active in the media stimulating debate and refuting the inaccurate, false and misleading claims of opponents of VAD law reform. Media has included an excellent interview by Leon Compton on the local ABC Mornings program, articles in the Age and Sydney Morning Herald, and other TV and radio interviews (eg The Project). Please contact us for a full list with links.

The most extensive coverage was the ABC’s Q&A on Monday 9 November. Andrew Denton appeared with Dr Rodney Syme, Vice-President of DwDV (and as we know a long term and passionate advocate for VAD laws), Dr Ralph McConaghy, a palliative care specialist, Dr Karen Hitchcock, author and clinician at the Alfred Hospital, and Ana Lamaro, a terminal cancer patient. The

program is no longer available on iView but key points have been picked up in the media.

Particularly important has been the FactCheck in the academic website, “The Conversation” that refuted the outrageous alarmist claim made by audience member, Luke Formosa, that the 2014 Netherlands euthanasia report revealed “550 newborn babies with diseases or disabilities were killed”. (<https://theconversation.com/factcheck-ganda-were-550-babies-killed-last-year-under-dutch-euthanasia-laws-50473> )

We’ve sent our thanks and congratulations to Andrew and will work to build on the significant boost he is providing to get voluntary assisted dying legislation in Australia.

#### **VICTORIAN INQUIRY INTO END OF LIFE CHOICES:**

The Parliamentary Committee inquiry set up in Victoria to examine “end of life choices” is receiving a vast amount of evidence in favour of voluntary assisted dying law reform as well as on advance care planning and palliative care. This is contained in submissions, of which over 1,000 were received, and in evidence at hearings. These are all available from the inquiry website (<http://www.parliament.vic.gov.au/lisic/article/2759>).

DwDTas made a long submission which is available on the website or contact us for a copy. According to figures presented to the inquiry by Neil Francis, DyingforChoice, in a hearing on 21 October, 96% of the submissions articulated a view on voluntary assisted dying, revealing the high level of community interest in the issue. Of those that mentioned it, 60.4% articulated a position in favour.

It's impossible in this newsletter to cover all of the excellent evidence. Among the most significant was that of the Victorian Coroners Court. Representatives presented details of their research showing evidence of dreadful suicides by people with incurable and irreversible medical conditions.

The Coroners Court study found that in 8.6% (197) of 2281 total suicides that came before the Court in the 4 year period from 1 Jan 2009 - 31 Dec 2012, "there was evidence that the deceased had experienced an irreversible deterioration in physical health due to disease or injury". The study did not include suicides due to mental health. In one case described at length at the hearing a 90 year old man died as a result of self-inflicted wounds from a nail gun. How truly shocking that someone would be so desperate and not have a choice of a peaceful, dignified death with his loving family.

The data and the case studies provide distressing facts like this that back up the large amount of anecdotal evidence of this terrible outcome of the lack of a legal option of voluntary assisted dying. You can access their submission with the detailed data on the website above and read their evidence at a hearing at [http://www.parliament.vic.gov.au/images/stories/committees/SCLSI/ELC\\_Transcripts/SCLSI - Coroners Court - FINAL - End-of-life choices 7 October 2015.pdf](http://www.parliament.vic.gov.au/images/stories/committees/SCLSI/ELC_Transcripts/SCLSI - Coroners Court - FINAL - End-of-life choices 7 October 2015.pdf).

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### NORTHERN HOSPICE

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We strongly support the ongoing development of palliative care services, and believe that people in the North and NW should have equity of access to hospice services as good as the Whittle Ward in Hobart. Friends of Northern Hospice and

Palliative Care Foundation have worked hard for some years to get a dedicated hospice in Launceston since the closure of the previous one at Philip Oakden House.

A study into the feasibility of a dedicated hospice in Northern Tasmania is now underway. This project has been funded by the Tasmanian Liberal Government as part of a pre-election commitment. The study will also examine potential hospice models "that meet quality and safety standards, and which could be sustainably delivered", current, unmet and future demand for hospice care facility to service the Northern region and existing hospice and palliative care services and the capacity of these services to meet the community need.

A public consultation survey has just closed but more information can be obtained from the consultants, Grosvenor Management Consulting on (03) 9616 2704.

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### PRESIDENT'S REPORT - JUNE - NOVEMBER

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As the first articles show, our optimism from the beginning of the year continues to be boosted - even with the setback in the UK and the frustration of slower local progress than we would like to enable all of us to have the comfort of a legal option of doctor-provided assisted dying to die with dignity as we see it, according to our own values, beliefs and what is important to us.

**AGM:** Our 2015 AGM was held on 7 August. Office bearers and Committee for 2015 - 16 were confirmed, the positive Auditor's report on our finances accepted and the special resolution was passed to increase annual dues to \$20 for individuals and \$30 for couples/families.

The AGM was followed by a very interesting guest presentation by Rosemary Sandford,

“Is Anybody Listening? Investment in Care of the Dying is an Investment in the Living and the Future”. As part of her presentation she proposed an action plan for end-of-life care in 21st century Tasmania. As Rosemary said in her address: “Sooner or later we will all die and I, for one, would like to know that I have been listened to by everyone involved in my care; that my dying wishes will be respected and acted upon; that I have ready access to quality, home and community-based end of life care; and that I can die how I wish in the place of my choosing.” We agree with her.

We also agree with her view that the delivery of palliative and end-of-life care services in Tasmania needs to adapt to changing times, improve equity of services across the State and better meet rapidly changing consumer expectations.

**WEBSITE:** I opened my last report in June with a plea for assistance with the maintenance of our website. Thank you very much to Maria Grist for her offer to help and for her assistance in taking on the maintenance, making some badly needed changes and her ongoing assistance. More updating is to be done.

News is being added more frequently to the website although we are chiefly using Facebook for quick updates, including sharing information from our Australian and overseas colleagues. If you use Facebook, ‘like’ us to stay in touch more frequently than is possible with the newsletter.

**END OF LIFE PLANNING:** We continue to get requests for the excellent end-of-life planning guide, developed by Bill Godfrey. You can download it from the website or contact us to have a copy mailed at a total cost of \$10.

**SUBMISSIONS:** In addition to the submission to the Victorian inquiry into end of life choices, DwDTas also made a submission to the Australian Human Rights Commission expressing concern about a Religious Freedom Roundtable process and guidelines. Only representatives of religious and spiritual organisations were to be invited, and one guiding principle supported the engagement of “individuals and communities of faith” with government and public agencies, not only to uphold the law, but also “to improve Australia’s moral and spiritual guidance”. We argued this is not consistent with the principle of freedom of thought, conscience and religion with equality before the law and protection of the freedom for those with diverse religious and non-faith beliefs. We are pleased to report that changes were made so that the roundtable process will involve much broader participation and the guiding principle was amended to remove the reference to spiritual or moral guidance.

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#### **OTHER NEWS FROM AROUND AUSTRALIA**

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**NATIONAL:** There has been no progress on the draft Medical Services (Dying with Dignity) Bill proposed by Senator Di Natale. We believe there is no chance that such a Bill would be passed in the current Federal Parliament and there is considerable doubt that it comes within Federal powers. We accept the strong legal view that it is a State issue and responsibility.

However, in a very welcome development, a new Bill has been moved by Senator Leyonjhelm to restore the rights of the Territories to consider and pass voluntary assisted dying legislation if they choose. The Federal Parliament clearly has the Constitutional power for such legislation. As you know, in 1997 the *Euthanasia Laws Act 1997* overturned the Northern Territory

*Rights of the Terminally Ill Act 1995* and removed the power from the NT, the ACT and Norfolk Island to make assisted dying laws.

**SA:** A new draft *Voluntary Euthanasia Bill* has been developed in SA by Labor MP, Stephanie Key, with our friends at SAVES (SA Voluntary Euthanasia Society). We will report on progress as it occurs.

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### **OTHER NEWS FROM OVERSEAS**

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**UK:** Contrary to the positive news from the US and Canada, the *UK Assisted Dying Bill 2015* was defeated in September by a vote of 330 to 118. The standard of the arguments against the Bill was extremely poor and the fear-mongering propaganda triumphed.

**QUEBEC, CANADA:** The Quebec law allowing voluntary assisted dying will come into effect on 10 December, 18 months after it was passed in an overwhelming vote of 94-22 in favour.

The law requires that patients are given information about the law and a referral and publicly funded health-care facilities

must provide assisted dying services. The lead-up to the law coming into effect has been marked by private palliative care services, particularly Catholic ones, announcing they will not allow access to assisted dying in their services.

The Quebec Medical Association which supports the law has expressed concern about the refusal to offer services and is arguing that “where there are rights, there are obligations” and “we need to ensure that the physician’s right to refuse does not become a denial of the patient’s rights.” (<https://www.amq.ca/en/qma-in-action/news/item/757> )

[Given that 57% of palliative care in Australia is provided by Catholic organisations (Source: Andrew Denton), this is a significant issue that the community will have to deal with when we get legal voluntary assisted dying law so that people’s freedom of choice under the law is not restricted by religious discrimination.]

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### **COMMITTEE FOR 2015 - 2016**

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

**Committee meetings:** We now hold our meetings in Kingston, at the Old School Building in Hutchins St (where U3A sessions are held). While they are usually scheduled for the second Wednesday in the month at 2 pm, there are occasional changes depending on the availability of members. We would love to see you at meetings but check first by ringing on the DwDTas number.