

Dying *with* Dignity



Tasmania (Inc)

JULY 2016

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ANNUAL GENERAL MEETING AND GUEST SPEAKERS - 19 AUGUST 2016 at 1.30 pm

We would be very pleased to see you at our AGM on Friday 19 August, commencing at 1.30 pm at the Nell Pascoe Room, Mathers Centre. See more details below. This will be followed by a public presentation and discussion about the new *Voluntary Assisted Dying Bill 2016* by its proponents, Lara Giddings and Cassy O'Connor.

We look forward to seeing as many of you as possible and hope you will invite others to come along. As always, while only members can vote and participate in the AGM, we welcome others to hear the very interesting presentation. There will also be afternoon tea following the public address and discussion.

Plea from the President for Committee and Office Bearer Nominations: We would love to see new people become involved on the Committee. Several of us are reaching the end of our very active involvement. This will be my last year as President.

At the end of the newsletter is a nomination form. Please contact me on the DwDTas number if you would like to know more or to register your interest.

YOUR RIGHT TO CHOOSE

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AGM and PRESENTATION

AGM - Purpose and Agenda

In accordance with the Constitution, the purpose of the AGM is to consider particular general business. The Agenda for the 2016 AGM is as follows:

1. Apologies
2. Confirmation of minutes of the last AGM, 7 August 2015
3. Annual reports
4. Election of committee members and Office Bearers
5. Appointment of Auditor

The venue is the same as the last three years, the Nell Pascoe Room, Criterion Centre. This is next to Mathers House, formerly called the 50 and Better Centre, between Criterion St and Bathurst St, Hobart. There is some parking, including disabled parking, off Bathurst St, just past the State Library. There is also good parking opposite in the Melville St car park.

PRESENTATION AND DISCUSSION

We are very pleased that Lara Giddings and Cassy O'Connor have agreed to make a presentation about the new Voluntary Assisted Dying Bill. At this stage we expect it will be very similar to the 2013 Bill. Its main provisions are very similar to the Canadian law and the legislative framework recommended by the Victorian inquiry into end of life choices. It includes stronger safeguards but not the unnecessary hurdles. DwdTas has continued to work with Lara and Cassy to finalise the Bill.

Come along with your friends and join in the discussion about the Bill and our campaign plans.

MEMBERSHIP

Our financial year ended on 31 May. Your membership is due only if you have received a renewal form with your hard copy or email. We would greatly appreciate your renewal as we continue to work for law reform and better end-of-life choices, information and services. Memberships are at the new rate agreed at the last AGM - \$20 for individuals and \$30 for family membership.

ARE WE THERE YET? NEARLY!

Just over a year ago we said the tide had turned in favour of voluntary assisted dying legislation. We can now see that it's well and truly flowing in! Watershed weeks don't get any bigger than from 9 - 17 June 2016.

- The Canadian legislation for medical assistance in dying was passed in the House of Commons on 9 June, then by the Senate and received Royal Assent on 17 June;
- The Californian *End of life Option Act* came into operation on 9 June;
- Also on 9 June, the Victorian Inquiry into end of life options presented its report to Parliament with recommendations for an assisted dying legislative framework, and the South Australian Premier spoke in the SA Parliament in favour of assisted dying legislation.

This all adds to the unstoppable momentum for assisted dying legislation in Australia. The question is which State will be first?

The major issue is also whether politicians have the compassion and courage to pass good legislation or whether they will succumb to the tactics of opponents to make access very limited and with many unnecessary and burdensome hurdles.

TASMANIA

The plan is still for the new Voluntary Assisted Dying Bill to be debated before the end of the year. Come and hear more on 19 August.

The Bill will be very similar to the 2013 Bill and we will let you know more details of and lobbying action in the next newsletter, before the Bill is moved in the Parliament. Those of you with online access can keep up with news through our website and Facebook page.

AUSTRALIA

South Australian BILL: High level support for the SA *Voluntary Euthanasia Bill 2016* has increased its chances of being passed. The Premier, Jay Weatherill, not only spoke in favour of such legislation in Parliament on 9 June but publicised his speech on his Facebook page where he said: *"I believe the South Australian Parliament should find a way to come up with laws that give genuine choice to those who are dying and that also put in place proper safeguards"*. In the debate, he also said: *"It seems to me that I must accede to the wishes, as I understand them, of people in my community who are asking me to give them the opportunity to take control of their lives and, in fact, the timing of the ending of their lives in circumstances where that end is near and they are the subject of, what in many cases feels like, unbearable suffering."* (Hansard, SA; 9 June 2016).

He is only the second Premier, after Lara Giddings, to provide this support. We understand that the Leader of the Opposition, Liberal Steven Marshall, has also expressed his in-principle support. The Bill is jointly supported by Labor MP Steph Key and Liberal MP Duncan McFetridge.

The former Liberal Leader, Isobel Redmond, has publically supported it, along with others from all the major parties.

The debate has of course attracted the usual irrational hysteria and fear-mongering fallacies. One MP, Liberal Adrian Pederick, went as far as making the delusional claim that allowing voluntary euthanasia would be a slippery slope to mass killings like those carried out in Nazi Germany.

Amendments to the Bill are likely and the debate still has some time to run. Only brief periods are made available in the SA Parliament for debate on private member's Bills.

VICTORIAN INQUIRY INTO END OF LIFE CHOICES

On 9 June, the Victorian Parliament Upper House Committee on Legal and Social Issues tabled an excellent report following its comprehensive, broad-ranging inquiry into end of life choices. You can access a copy of the full report or a summary at <http://www.parliament.vic.gov.au/lsc/inquiry/402>.

The Committee's 49 recommendations cover many areas - palliative care, advance care directives, legislative issues (eg right to refuse treatment), and the need for assisted dying legislation.

The recommendation of great interest and significance to us is 49: *"That the Victorian Government introduce a legal framework providing for assisted dying, by enacting legislation based on the assisted dying framework outlined in this Report"*.

This is a tremendous step forward for assisted dying legislation not only in Victoria but across Australia. Although its findings are consistent with all other thorough reputable reviews of the last few years, it's the first Australian parliamentary

committee one to recommend legislation and to argue for it strongly on the basis of core values and overwhelming evidence. This includes evidence, illustrated with many personal stories, about the need for the law, the dreadful consequences of not having a legal assisted dying option and that regulated, transparent assisted dying systems have been safe and can provide a safe, responsible option in Australia.

As the report says:

- *While several submissions suggested that all pain and suffering can be alleviated through the provision of better palliative care, the Committee heard from health practitioners that not all pain can be alleviated. Palliative care cannot always be the solution to managing pain and suffering at the end of life. (pxxvii)*
- *Prohibition of assisted dying is causing some people great pain and suffering. It is also leading some to end their lives prematurely and in distressing ways. (pxx)*
- *Family members, the Coroners Court of Victoria and Victoria Police gave evidence about how people experiencing an irreversible deterioration in health are taking their own lives in desperate but determined circumstances. (p193)*
- *The Committee is satisfied, through its research into international jurisdictions, that assisted dying is currently provided in robust, transparent, accountable frameworks. The reporting directly from such frameworks, and the academic literature analysing them, shows that the risks are guarded against, and that robust frameworks help to prevent abuse. (p212)*
- *The Australian Christian Lobby, the Catholic Archdiocese of Melbourne,*

Doctors Opposed to Euthanasia, the Australian Catholic Bishops Conference, and the Australian Family Association, amongst others, suggested that safeguards in assisted dying frameworks cannot provide adequate protection for the vulnerable. ... While their concerns about the safety of vulnerable people and the need for them to be protected are valid and should inform the design of any assisted dying framework, the Committee did not find evidence to support these concerns. (References omitted; p213)

- *We found no evidence of institutional corrosion or the often cited ‘slippery slope’. (pxvii)*
- *Instances of assisted dying are rare, even in jurisdictions where it is legal. (pxx)*
- *The evidence is clear that assisted dying can be provided in a way that guards against abuse and protects the vulnerable in our community in a way that unlawful and unregulated assisted dying does not. (p212)*

The framework recommended is similar to the Tasmanian Bill and the Canadian legislation in many ways. However, there are some parts that are concerning because they are inconsistent with the principles and rationale outlined by the Committee and available evidence. In particular they are inconsistent with the evidence from the Victorian Coroners Court which the Committee had found “highly persuasive”.

Of greatest concern is the recommendation that, to access assisted dying, people would have to be “at the end of life (final weeks or months of life)”. The medical literature includes article after article about how difficult, if not impossible, it is for doctors to predict time to death with any certainty.

The vast majority of people who access assisted dying overseas - and are likely to access assisted dying here - are close to death. But there is a small percentage of people, like Tasmanian Elizabeth Godfrey, who are experiencing intolerable and unrelievable suffering due to incurable and irreversible chronic conditions. The end of their life is not foreseeable, or certainly not within months or weeks, and yet their quality of life is extremely poor and unacceptable to them. They want their wishes respected for a dignified and peaceful death, not to have to face suicide as the only option left to them to achieve this.

According to the Victorian report: *“The Coroner’s Court told the Committee that some Victorians are ending their lives in dreadful ways. Many of these people identified by the Coroner are dying alone and in pain. They are often dying earlier than they desire because they believe they must act alone, before they are no longer capable, and so that their loved ones are not implicated in their death”*. What the Victorian Committee does not seem to have taken into account is that death was not foreseeable for 60% of the suicides referred to in the Coroners Court evidence. (You can access the Coroner’s Court submission at http://www.parliament.vic.gov.au/images/Submission_755_-_Coroners_Court_of_Victoria.pdf and 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.)

The Victorian Government has 6 months to respond to the recommendation for assisted dying legislation. It has already acted on by issuing consultation papers on advance care directives and palliative care. On 26 June, it issued for public consultation a position paper, *“Simplifying medical treatment decision making and advance care planning”*. Much of the paper is

excellent but it includes a bizarre and inconsistent proposal that “palliative care” will not be included in the definition of medical treatment, and therefore medical treatment decision makers (eg enduring guardians) would not be able to refuse palliative care for the people they speak for when they are no longer able to speak for themselves.

NSW: A cross-party NSW Parliamentary Working Group on Assisted Dying has been formed and is working towards another assisted dying Bill.

Queensland: We understand that a Private Member’s assisted dying Bill is possible in Queensland in the coming year.

NATIONAL PROJECT: As you may be aware, Andrew Denton has continued his very active and valuable advocacy for assisted dying laws. He has also initiated a national project to provide assistance across the States to achieve law reform. There will be national action, including a website, social media assistance and resources. The project is already providing assistance to our colleagues in SA and will assist us in similar ways closer to the time of the Bill.

We are very pleased that what we asked for as our major priority is being acted on. We asked for a database of personal examples of the prolonged intolerable suffering that people are being forced to endure and of other terrible consequences when we don’t have a legal assisted dying option. On 10 August, Andrew Denton will speak at the National Press Club at 12.30 in an address entitled *‘The Damage Done – The price our community pays without a law for assisted dying’*. It will also be streamed live on TV on ABC24. He will launch a book of 65 testimonies (from families, friends, coroners, doctors and nurses) detailing the suicides, the horrible deaths, the lingering untreatable suffering, and the lie that

palliative care is the answer for everything. It will be in the vicinity of 130 pages long. This builds on his 17-part podcast series “Better Off Dead”. The transcripts of the series are also now available at <http://www.dwdnsw.org.au/andrew-denton-shares-results-of-his-major-research-project/>.

AMA REVIEW OF POLICY: The AMA review of its policy on assisted dying is proceeding but not in a way which is consistent with the excellent example of the Canadian Medical Association. The survey of members failed to meet acceptable professional standards and is unlikely to produce reliable results. For example, the definition of ‘euthanasia’ used in the survey was different from the AMA’s own definition and bore no resemblance to the provisions of any assisted dying legislation or Bills.

OVERSEAS

CANADA: In a tremendous step forward for assisted dying law reform, the Canadian law for ‘medical assistance in dying’ has been passed and received Royal Assent on 17 June. In the words of the Minister for Justice, the law:

- *First, it would permit physicians and nurse practitioners to provide medical assistance in dying, so that patients who are suffering intolerably from a serious medical condition, and whose death is reasonably foreseeable given all of their medical circumstances, can have a peaceful death and not be forced to endure slow and painful suffering. Second, it would commit to study the other situations in which a request for medical assistance in dying might be made. [This includes through an advance request, requests by ‘mature minors’ and requests when mental illness is the **only** medical condition]*

- *To be clear, the bill does not require that people be dying from a fatal illness or disease or be terminally ill. Rather, it uses more flexible wording; namely, that “their natural death has become reasonably foreseeable, taking into account all of their medical circumstances”. This language was deliberately chosen to ensure that people who are on a trajectory toward death in a wide range of circumstances can choose a peaceful death instead of having to endure a long or painful one.*

The requirement for death to be “foreseeable” is the most contentious part of the law as an unnecessary hurdle. Many MPs and others outside the Parliament have argued that this is more restrictive than the original Supreme Court decision that precipitated the law. It is already causing some people to live with prolonged suffering and is being contested in the courts.

The Quebec assisted dying law continues to be implemented and will stay in operation although there is now national legislation.

CALIFORNIA: The Californian *End of Life Option Act* came into operation on 9 June 2016, having been signed into law in October 2015 by Catholic Governor, Jerry Brown. The law provides virtually the same legal assisted dying option as that available in other US States, Oregon, Washington, Vermont and Montana. That is, people with a terminal illness with less than 6 months to live may be able to get from their doctor a prescription for lethal drugs they can take themselves.

NZ: The NZ Parliamentary inquiry into the draft *End of Life Choice Bill* has attracted over 20,000 responses. There is therefore a delay in finalising the review.

**PARLIAMENTARY COMMITTEE “INQUIRY
INTO PALLIATIVE CARE”**

DwDTas has made a submission to the House of Assembly Committee “Inquiry into Palliative Care”. The title is a misnomer because the terms of reference are very limited. There has also been very limited publicity about the inquiry. There appears to be no intention to produce something as impressive and comprehensive as the Victorian inquiry and therefore the inquiry is likely to have limited value. Our concern is that it must not be used as an excuse to delay consideration of the new voluntary assisted dying Bill.

The terms of reference are:

To inquire into and report upon the matter of care of palliative patients generally, specifically the matters of:

- (i) advance care directives;
- (ii) administration of medical treatments to minors;
- (iii) the administration of emergency medical treatment; and,
- (iv) other matters incidental thereto.

In our submission we expressed strong support for palliative care and focussed on three critical issues:

1. The need to consider the broad context in which the care of palliative patients is occurring and is likely to occur, particularly significant changes and challenges, and to utilise quality information.
2. Respecting and meeting the needs and expressed wishes of palliative patients whose serious intolerable suffering cannot be relieved adequately by means acceptable to them.

3. Respect, commitment and requirements that people’s wishes be met not just support for people to state their wishes.

Please contact us if you would like a copy of the submission.

END OF LIFE ISSUES

Northern Hospice: Achievement of a dedicated Northern hospice has had a major setback with a report of a feasibility study recommending against it. This was a bitter blow to the hard-working Northern Hospice and Palliative Care Foundation which has for years advocated for a dedicated hospice in Launceston since the closure of the previous one at Philip Oakden House. There have been major criticisms of the report as failing to include critically relevant data and failing to address key issues such as the difference between a dedicated hospice and a unit within a hospital, especially a Catholic private hospital.

DwDTas will continue to support a Northern hospice of the same model and quality as the Whittle Ward in the South.

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. Bill has offered his information sessions and workshop to numerous groups and has recently conducted a session for the Geeveston Seniors group.

If you are a member of a group, or know of a group that may be interested, please let us know.

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

Committee meetings: The next meeting is scheduled for 10 August. We now hold our meetings in Kingston, in D Building, Old School Building in Hutchins St. 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.

Please detach - - - - -

Dying with Dignity Tasmania Inc - Proposal Form for Positions 2016 – 2017

Name of nominated member:

Signed: **Signature of nominee**

For the position of:
(President/Vice President/Secretary/Treasurer/General Committee)

Name of Proposer member:

Signed:

Name of Seconder member:

Signed:

Date:/...../ 2016

Please mail this form to: DwDTas, PO Box 1022, Sandy Bay, Tasmania 7006, by 12 August 2016.