



**RESPONSE TO
THE VICTORIAN DISCUSSION PAPER:
VOLUNTARY ASSISTED DYING BILL**

APRIL 2017

YOUR RIGHT TO CHOOSE

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SUMMARY

- The Tasmanian *Voluntary Assisted Dying Bill 2016* was moved in the Parliament on 17 November 2016. At the time of writing, a date has not yet been set for the Parliamentary debate but we are lobbying for this to be as soon as possible.
- The Bill represents one very detailed way that the issues and questions raised in the Discussion Paper on the Victorian Voluntary Assisted Dying Bill have been resolved. This has been specifically for the Tasmanian situation but this has close similarities to the Victorian one, especially in relevant community values and medical and legal systems. We believe this will be useful for the Panel because, as we found, it was only at the time of drafting of legislation and discussion of detailed provisions that there was clarity and shared understanding about key matters. A copy of the Bill is attached to this response as well as links to it.
- The Bill is largely based on the *Voluntary Assisted Dying Bill 2013*, which narrowly failed to pass in the Tasmanian House of Assembly when all Liberal MPs voted against it. That Bill was preceded by an intensive process of research and consideration, a detailed Proposal and rationale and public consultation, outlined in the Proposal for the legislation. The 2016 Bill is the result of over 6 years work, by people with high level skills and experience in policy and legislation, and is based on thorough research and ongoing monitoring and critical analysis of the overseas situation and in Australia. The evidence to and findings of the Victorian inquiry into end of life choices has added to the research and has generally confirmed and reinforced the approach taken in the 2013 Bill and the subsequent amendments for the 2016 Bill. A different approach has been taken in the Tasmanian Bill on a few aspects consistent with the aims, focus and key considerations.
- This response is relatively brief. This is a very busy time for us because of the possibility of debate on the Bill soon. The President of DwDTas, Margaret Sing, who has been very closely involved would be happy to provide more details or discuss matters further. She has provided a great deal of the research and analysis, worked in the small expert team for the 2013 and has provided most of the support to MPs for the 2016 Bill as amended.
- The response includes as an attachment a detailed comparison of safeguards in the Tasmanian Bill with overseas legislation and the recommended assisted dying framework for Victoria. It also includes background information and information on the Tasmanian *Voluntary Assisted Dying Bill 2016*, including the current situation, aims and key considerations and rationale with a particular focus on access and eligibility.
- The Bill takes a principles- and evidence-based approach with the primary aim of providing a 'last resort' option for people at the end of their lives who have intolerable and unrelievable suffering and for their doctors to end that suffering through assisted deaths.

BACKGROUND INFORMATION

- Dying with Dignity Tasmania has been closely involved in the issue of Tasmanian voluntary assisted dying legislation for many years. We became much more involved after the *Dying with Dignity Bill 2009*, which failed to pass.
- We had a great deal of involvement in the development of the [proposal for the 2013 Voluntary Assisted Dying Bill](#) and the Bill itself and, most recently, the *Voluntary Assisted Dying Bill 2016*. This involvement has included working with the experienced senior politicians committed to the legislation and their staff, including Lara Giddings, Premier of Tasmania, when she co-sponsored the 2013 Private Members Bill, the first Premier to do so. Co-sponsor of the 2013 Bill was Nick McKim, then Leader of the Greens and Minister for Education and Skills. He is now a Senator. For the 2016 Bill, the current co-sponsor is Cassy O'Connor, Leader of the Greens. Senior staff from their offices with high level skills and experience worked on the 2013 Proposal and Bill, with an expert panel.
- The close involvement of DwDTas has been through the President for the last 6 years, Margaret Sing. Related to but separate from her position in DwDTas, she has had very close involvement in a personal capacity in the Tasmanian voluntary assisted dying legislation over that period because of her background as a former senior public servant with over 40 years' experience with policy, legislation and politics. This has included involvement in review and oversight boards and committees. Margaret has made major contributions at every stage of the processes for the finalisation of the 2016 Bill and the prior 2013 Bill and Proposal as acknowledged in the Parliament by the MPs involved.
- DwDTas provided a [detailed submission](#) to the Victorian inquiry into end of life choices in August 2015. It included more detailed information about DwDTas and its relevant activities along with a range of other comment and information, including our arguments in favour of voluntary assisted dying legislation, the Tasmanian experience and then current situation.
- The evidence to the Victorian inquiry and its excellent report and findings have provided valuable material for the finalisation of the Tasmanian *Voluntary Assisted Dying Bill 2016* and has confirmed and reinforced our approach to the Tasmanian Bill, including in areas where we reached a different conclusion. This is chiefly in relation to access and eligibility, administration of the drugs and the oversight, reporting and monitoring.
- We have also continued to research and analyse other developments from a policy and political perspective, such as Parliamentary debates, including the Canadian and the recent SA debates, and the implementation of both the Quebec provincial legislation and the Canadian medical aid in dying legislation which was passed after the Victorian inquiry had completed its work.
- We commented in our submission to the Victorian inquiry on our assessment of the key characteristics of the campaign against voluntary assisted dying legislation. They are also relevant to the kind of legislation and details that are currently being developed for the Victorian Voluntary Assisted dying Bill:
 1. the failure of opponents to acknowledge the people who are at the end of their lives with intolerable and unrelievable suffering, or to respond with empathy, kindness or respect for them

2. the absence of evidence of respect for doctors or trust in their meeting professional, ethical and legal requirements and standards in our regulated medical system and within the additionally regulated oversight, scrutiny and reporting of voluntary assisted dying laws
 3. the absence of evidence for their arguments and claims against voluntary assisted dying legislation and proposed legislation, and absence of evidence of reasonable assumptions, realistic risk assessment or adequate knowledge and understanding of existing legislation, or of the details of proposed Bills, including the multiple safeguards.
- We have continued to analyse the campaigns against voluntary assisted dying legislation and note the core strategies used by opponents and which are relevant to your consideration of the details of the Victorian Assisted Dying Bill. The strategy of ‘delay, obstruct and restrict’ has come to the fore wherever legislation has become inevitable (eg Canada) and where it has become likely. The aim is to delay legislation (eg claims that more research/consultation is necessary, something else is more important, etc), obstruct the progress of Bills (eg large number of amendments moved to Bills), and trying to get the most restrictive legislation possible, regardless of the impact on people with terrible suffering and regardless of the fact that the restrictions are not justified by effective risk assessment.
 - In Canada, for example, key opponents argued for eligibility to be restricted in the community debate, the public consultations and by MPs in the Parliamentary debate. For example, key Catholic opponent, Margaret Somerville, who has now returned to Australia and is very actively opposing legislation here, and others argued to the Canadian Joint Select Committee on Physician-assisted Dying that “only individuals with less than four weeks to live should qualify” and only those experiencing “physical suffering”, that medical assistance in dying should be provided only by doctors “within a defined and regulated medical subspecialty” and that each request “should be reviewed by some type of panel or a judge”¹. The Joint Select Committee and the Parliament rejected all these restrictions. Others such as the Physicians’ Alliance against Euthanasia and the Euthanasia Prevention Coalition have “argued in favour of allowing only assisted suicide”² [ie only self-administration as in Oregon and other US States]. The Canadian legislation does not have this restriction. The Quebec provincial legislation does not allow self-administration of the lethal drugs but only doctor-administered drugs for voluntary assisted dying.
 - The strategy of trying to get the most restricted eligibility relies on the other two common strategies of the campaign against voluntary assisted dying legislation.
 1. The foundation strategy is cover-up, strategic omissions and distortion of key facts and arguments in order to promote the view that the legislation isn’t necessary. The most important strategic omissions are the failure to acknowledge the people who are at the end of their lives with intolerable and unrelievable suffering, in Australia and in relation to overseas legislation (eg focus on increases in numbers and a small number of examples of claimed abuses but with no mention of the fact that each of those numbers and examples represents a person with great suffering).
 2. The fear-mongering strategy is very obvious and promotes the view that the legislation is too dangerous. It relies on very poor data, knowledge and understanding of both overseas legislation and what is being proposed, and fails to provide evidence or a reasonable basis for claims such as ‘slippery slope’, that assisted dying legislation cannot be made safe, etc.

¹ See <http://www.parl.gc.ca/content/hoc/Committee/421/PDAM/Reports/RP8120006/pdamrp01/pdamrp01-e.pdf>, p12, 15, 28 and 30

² See External Panel Final Report on Consultations, <http://www.justice.gc.ca/eng/rp-pr/other-autre/pad-amm/pad.pdf> p49.

TASMANIAN VOLUNTARY ASSISTED DYING BILL 2016

Current situation

- The Tasmanian *Voluntary Assisted Dying Bill 2016* was moved in the Tasmanian House of Assembly on 17 November 2016, as a Private Members Bill co-sponsored by Lara Giddings, former Premier and Labor MP for Franklin, and Cassy O'Connor, Leader of the Greens and MP for Denison. It does not yet have a Liberal sponsor but it is hoped that this will happen before the debate on the Bill.
- Timing of the debate is not yet settled. At the time of writing this response, we hope this will be the first week in May.
- Detailed supporting information for the Bill including fact sheets and clause notes is being prepared. DwDTas is finalising its own material including Issues Papers and website updates that provide more detailed supporting information. On our website currently, you will find supporting information including a [brief summary of the Bill](#), and Issues Paper 1, [Voluntary Assisted Dying – The Basics](#). Other sections relevant to this response include:
 - Real stories including Tasmanian and Australian stories, overseas examples and “Desperate measures” which includes details of the Victorian Coroner’s evidence
 - Key reports and resources
 - Canada
 - Current situation in Australia on voluntary assisted dying.
- A section on the current situation overseas is being finalised.

Overview

- The Tasmanian *Voluntary Assisted Dying Bill 2016* represents one very detailed way that the issues and questions raised in the Discussion Paper on the Victorian Voluntary Assisted Dying Bill have been resolved. This has been specifically for the Tasmanian situation but this has close similarities to the Victorian one, especially in relevant community values and medical and legal systems. We believe this will be useful for the Panel because, as we found, it was only at the time of drafting of legislation and discussion of detailed provisions that there was clarity and shared understanding about key matters.
- The Bill is principles- and evidence-based, consistent with community views as expressed in multiple, repeated opinion surveys and testimonials, and designed to be practical and workable in the Tasmanian situation.
- The Bill is largely based on the *Voluntary Assisted Dying Bill 2013*, which narrowly failed to pass in the Tasmanian House of Assembly when all Liberal MPs voted against it. That Bill was preceded by an intensive process of research and consideration, a detailed Proposal and rationale and public consultation, outlined in the Proposal for the legislation. The 2016 Bill is the result of over 6 years work, by people with high level skills and experience in policy and legislation, and is based on thorough research and ongoing monitoring and critical analysis of the overseas situation and in Australia. The evidence to and findings of the Victorian inquiry into end of life choices has added to the research and has generally confirmed and reinforced the approach taken in the 2013 Bill and the subsequent amendments for the 2016 Bill. A

different approach has been taken in the Tasmanian Bill on a few aspects consistent with the aims, focus and key considerations.

- A copy of the Bill is attached to this response and available through [this link](#) or from the Tasmanian Parliament website.
- Also attached is a detailed [Comparison of Voluntary Assisted Dying Safeguards](#). This detailed comparison is of key safeguards in the 2016 Tasmanian Bill with those in overseas legislation and the assisted dying framework recommended in the 2016 report of the Victorian inquiry into end of life choices. The comparison shows that the provisions of Tasmanian Bill are consistent with both overseas legislation and the recommendations of the Victorian inquiry but there are also significant differences. We draw your attention in particular to the sections on:
 - Eligible medical condition (p8)
 - Regulatory monitoring, scrutiny and reporting (p10)
 - Type of assistance (p12).

Aims of the Tasmanian Bill

The aims of the Bill show the core focus on the people at the end of their lives with terrible suffering and consistency with the values of empathy and respect for them and their doctors.

1. The principal aim of the Bill is to provide a ‘last resort’ option for people at the end of their lives and their doctors to end intolerable and unrelievable suffering through assisted deaths.
2. Although only a small proportion of people at the end of their lives will need or want assisted dying, it aims to also provide comfort which can have a palliative effect when people know there may be an option for them if they end up with intolerable and unrelievable suffering and have no chance of recovery or relief.
3. Reflecting what we now know based on the Victorian Coroners evidence, an aim is to prevent desperate suicides with their devastating consequences.
4. Reflecting other evidence, another aim is to protect doctors, families and others from the risk and considerable fear of prosecutions for acts of compassion and kindness that may be regarded as criminal acts under the current law.

Key considerations and rationale

1. The Bill has multiple safeguards to ensure that only those who are eligible will receive assisted dying and that those who don’t want it will not receive it:
 - People must be competent adults, and make voluntary, informed and repeated self-initiated requests, all of which must be eligible requests.
 - The system is doctor-safeguarded by at least two doctors, voluntarily responding to and thoroughly exploring requests, and with significant responsibilities in ensuring eligibility requirements are met and reported on.
 - There is the additional safeguard of independent oversight, monitoring and reporting by a Registrar with significant statutory powers and responsibilities.

2. 'Last resort' option for people at the end of their lives with intolerable and unrelievable suffering
- This model best represents Tasmanian community views and doctor views as we know them. A DwDTas paper of April 2015, [Support for Voluntary Assisted Dying Law Reform](#), provides details of the community support for this 'last resort' approach. It is hoped to update this soon to reflect the views of doctors nationally as surveyed by the AMA last year. Although the survey results are limited and there have been strong criticisms of the poor design and very low response rate, they are the best information we have on current doctor views. We have noted in particular that: "For those who agreed euthanasia and physician assisted suicide should be provided by doctors, the vast majority (> 90%) supported it in the case of a person suffering an incurable illness associated with unrelievable and unbearable suffering' while less (<71%) supported it for a terminal illness (Survey Questions 8 and 17)." (p8, Review of AMA Policy on Euthanasia and Physician Assisted Suicide report)
 - It would provide eligibility for people who are well known to us and who have been exemplars of the harm done by the lack of a voluntary assisted dying option (eg [Elizabeth Godfrey](#) and [Robert Cordover](#)) and currently in need of such an option (eg [Joan Fitz-Nead](#))
 - The model is closest to the [Canadian Supreme Court decision](#) in February 2015 and to the Canadian Medical Association [Principles-based Recommendations for a Canadian Approach to Assisted Dying](#). The work of the Canadian Medical Association has been of a particularly outstanding profession and ethical standard, which has, disappointingly, not been replicated by the AMA. Canada is much closer than other places with assisted dying legislation to Australia culturally, historically and politically. The in-depth reviews and reports from Canada on the issue of assisted dying are numerous and of a very high standard. See our website section, [Key Reports and Resources](#).
 - Oregon is seen by many people as providing an acceptable model, but this is often based on limited knowledge, understanding and critical analysis. Our critical in-depth analysis of all overseas legislation and the data on outcomes resulted in a rejection of the Oregon model (now replicated in other US States) in particular. It is not suitable or not effective enough for the Australian situation for a number of reasons. We hope to have the critical assessment on the website soon but in brief:
 - It suits the dominant American cultural value of individual autonomy and self-reliance and responsibility. Although compassion and concern for people with great suffering has been part of the justification for the legislation, there is no requirement to demonstrate suffering, let alone intolerable and unrelievable suffering.
 - It is the only model of legislation that requires terminal illness and a prognosis of a specific timeframe to death, and this requirement seriously disadvantages people who are otherwise at the end of their lives with terrible suffering but for whom such a prognosis is difficult or impossible for doctors to provide.
 - The model would not meet the aim of preventing many of the desperate suicides described by the Victorian Coroner or known to us. (See stories on our website in particular the Tasmanian ones of Elizabeth Godfrey and Robert Cordover.)

- It reflects the American medical system which is different from the Australian system. For example, as reported by the Victorian inquiry: "*doctors in Oregon told the Committee that the requirement that a patient be within six months of death to access assisted dying is based not on a medical judgement, but on the fact that federal funding for hospice care is available to Oregonians at that point*" (page 223). This "*is not applicable to the Australian context which provides universal health care*". (page 224) As also commented: "*a patient in Oregon can receive a prescription for a lethal drug and choose not to see their doctor again. This is because choosing the level of interaction with a doctor reflects the value of self-determination that is fundamental in American culture*" (page 217).
- It meets the needs of a relatively small number of people compared to other jurisdictions and predominantly those who are white and with higher educational qualifications.
- It allows only self-administration of drugs by oral ingestion, even though the most effective drugs are not available or are very expensive, and are increasingly out of the reach of many people. See for example [this article](#).

There is evidence of very unsatisfactory complications and no requirement for a doctor to be present to provide medical support to deal with such complications. The less satisfactory drugs used involve up to 100 capsules or a cocktail of drugs prepared by individual pharmacists. This causes major problems for the people concerned and their families or others who help them. [This article](#) reports one experience under the recently passed Colorado law where it took an hour and a half to break and empty the 100 gel capsules.

Also there are very unsatisfactory complications with oral ingestion with the affordable drugs (eg regurgitations) and without medical support available if they do occur because doctors do not have to be present. However, the data is limited and concerning. As the [latest annual report](#) shows, data on complications is only collected when a "health-care provider" is present. Yet the report shows that since the law came into effect there have been 30 people (of a total 1,127 - 2.6%) who had difficulty ingesting the drugs or regurgitated them. An additional 6 people regained consciousness after ingesting prescribed lethal medications.

- The Tasmanian Bill provides eligibility for **people at the end of their lives**, that is, at the end of lives that will ever again be free of intolerable and unrelievable suffering, and ever again be free of the devastating effects of the advantaged stages of serious, incurable and irreversible medical conditions. This reflects the fact that what is more important to people in this situation is the quality of their lives not quantity.
- The Tasmanian model does not use terms such as 'terminal illness', 'end of life' or 'foreseeable death' and does not require a prognosis of a particular timeframe for the following reasons:
 - 'Terminal illness' – the term is used by different people to mean different things including 'inevitable fatal', end stages of an inevitably fatal illness, the illness of someone nearing death or of someone within a particular timeframe varying from years to weeks.
 - 'End of life' and 'foreseeable death' – too vague and imprecise, too open to different interpretations with potential for unnecessary conflict between the two doctors that

must be involved, to the detriment of the person requesting assisted dying, and difficult for the oversight body to determine with any reliability. 'End of life' is too abstract and not related to what the people concerned believe is the end of their lives.

- Prognosis – too unreliable a criterion for legislation, the Oregon reports show it doesn't work as a reliable criterion, it unfairly disadvantages people with terrible suffering and has been rejected as criterion by all other jurisdictions including for the Canadian legislation. For example, the [latest annual report](#) in Oregon shows that the duration between first request and death has been as long as 1,009 days (over 2 and a half years). This is understandable because prognoses of this kind are acknowledged by doctors to be difficult and unreliable and it is often undesirable for them to be provided to the patient because of this unreliability.
3. The Tasmanian Bill provides for both self-administration and doctor administration because of the issues in Oregon. It is still not clear to us that Nembutal will be available or affordable for Australian prescription and use. Self-administration only by oral ingestion is too limited and the Tasmanian Bill provides for the use of a medical device (eg syringe driver) activated by the person to administer the drugs.
 4. The Tasmanian Bill requires doctors to be present even when the drugs are self-administered. We are aware of concerns about this including the 'medicalisation' of the process, a preference for nurses rather than doctors to be present if medical professionals are required, and the problems that could occur if the doctors are away or otherwise not available at the time chosen by the person to self-administer. From our consultation with local doctors who are in favour of assisted dying and would be prepared to provide, they have concerns about the demands on them particularly when there may be few doctors prepared to provide the service, particularly in the early days. We will be reporting these concerns to the MPs sponsoring the Bill.
 5. A panel system of oversight was rejected for the Tasmanian Bill as:
 - too cumbersome and expensive
 - too difficult to determine fair and equal representation of views
 - less effective than statutory independent oversight when there is a small number of cases, and
 - in a place as small as Tasmania, too subject to overlapping social and professional connections to be seen as independent and objective.