



SUBMISSION TO THE STANDING COMMITTEE ON COMMUNITY DEVELOPMENT INQUIRY INTO PALLIATIVE CARE

Terms of Reference:

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.*

JUNE 2016

SUBMISSION TO THE “INQUIRY INTO PALLIATIVE CARE”

OVERVIEW

- Our submission is relatively brief and we request the opportunity to appear at a hearing to speak to the points we make below, to make additional points we would like to raise after a thorough consideration of the recently published Victorian Parliamentary inquiry report into end of life choices¹, to answer questions and respond on other matters of interest to the Committee.
- We have not addressed the issue of voluntary assisted dying legislation in detail because that will be dealt with in the lead-up to the new Bill later this year. We refer to the issue where relevant and would be happy to address any specific questions and concerns of the Committee about voluntary assisted dying legislation either on request or at a hearing.
- The Committee can play a valuable and important role in the lead-up to the debate on the Bill by ensuring that accurate information is provided to MPs and the public that is relevant to its own terms of reference and to assisted dying. Voluntary assisted dying exists on a continuum of person-centred care, including care of palliative patients, and is underpinned by the same principles and values as that care and the specific matters being considered by the Committee. Core principles and values need to be identified and supported and information provided on other important relevant matters, particularly:
 - the evidence that there are people whose intolerable suffering from incurable and irreversible medical conditions cannot be relieved adequately by palliative care or other medical treatment, our community response to them has been seriously inadequate and there are serious and unacceptable risks in not responding effectively to their needs and wishes
 - there is consistent and overwhelming evidence that feared abuses and negative impacts of assisted dying legislation have not eventuated. The Victorian Parliamentary Inquiry into end of life choices, whose report was tabled on 9 June 2016, is the latest in a number of thorough, reputable reviews to reach this conclusion:
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. 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. (page 212)
- DwDTas strongly supports palliative care and recognises the quality of care that is provided in Tasmania. We recognise that palliative care is only a part of end of life care, though a valued and essential part, that assists many people to have the peaceful and dignified end that they wish for, as well as providing valuable support for their families and loved ones.

¹ The report is available at <http://www.parliament.vic.gov.au/lsc/inquiry/402>, along with detailed information on terms of reference, submissions, hearings and transcripts.

We also recognise that palliative care, no matter how good it is, is unable to relieve all suffering adequately and to the satisfaction of the people concerned.

- We recognise, support and have contributed to the excellent ongoing work of many people in the State towards maintaining and developing policy and services related to the Committee's terms of reference. We recognise that there are gaps, inequities and significant and increasing challenges to provide the range of palliative care services to meet needs across the State, to the same level and standard as those in Hobart. We expect that many submissions will provide you with expert information and advice on matters such as:
 - The excellent work being done by Professor Michael Ashby and colleagues on many matters including the Healthy Dying Initiative
 - Improvement and increase in the range of palliative services in the State through the Better Access to Palliative Care Program and also the challenges such as security and sustainability of funding
 - The new project to develop a Community Charter for palliative care in Tasmania
 - The case for a dedicated hospice in the North as advocated so impressively by the Friends of Northern Hospice and Palliative Care Foundation
 - Promotion of, and encouragement and support for people to appoint an Enduring Guardian and otherwise undertake advance care and end of life planning.
- In this submission we have focussed on three critical issues for the Committee to consider and which may not be covered in other submissions.
 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. We recommend that the starting point for the Committee's deliberations should be consideration and adopting of the core values for end of life care proposed by the Victorian Parliamentary Inquiry into end of life choices.
 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.

BACKGROUND INFORMATION

Although Dying with Dignity Tasmania Inc is well known for its advocacy of voluntary assisted dying law reform, it has been very active in promoting, encouraging and supporting people in a practical way to undertake end of life and advance care planning and has a focus across end-of-life issues, including improved end-of-life care services such as palliative care. Our basic objects are to support, promote and work for:

- the right of everyone to make decisions about their death and dying with the same freedom of choice, personal autonomy and human rights that they have in other aspects of their lives
- the right of everyone to die with dignity, as they see it
- end-of-life and advance care planning to enable everyone to express their wishes and to have them respected

- accessible, quality services, including palliative care, that assist people to have a dying process and death they regard as dignified, and
- law reform consistent with the objects above.

DwDTas is a volunteer organisation run by an active Committee from a wide range of backgrounds and experiences, including medical, professional, public sector, business and community. The Committee and other members have diverse religious and philosophical views. More details can be found at our website, www.dwdtas.org.au.

DwDTas has been very actively involved for many years in support of voluntary assisted dying legislation. Voluntary assisted dying legislation is most relevant to the current inquiry because it recognises and provides an option for palliative patients whose suffering cannot be relieved adequately despite the best intentions, skills and efforts of palliative care and/or other medical personnel and services. We have provided as an attachment to this submission a copy of the “DwDTas position on VAD law reform - summary June 2016”. This has been updated to include the most recent developments - all on 9 June 2016 - the passing of the Canadian legislation to provide ‘medically assisted dying’, the Californian *End of Life Option Act* came into effect and the report of the Victorian Parliament’s Legal and Social Issues Committee inquiry into end of life choices was tabled which, among other things, recommended an assisted dying legislative framework.

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

It is impossible to effectively consider the terms of reference generally, or the specific matters of interest, without taking into account the broad context and environment in which the care of palliative patients is occurring now and in the foreseeable future. There have been and are likely to be many changes and challenges that impact on this care, including medical, social, cultural, demographic and attitudinal, as well as the broad economic and fiscal pressures on the State and Federal Governments.

While addressing these changes and challenges in detail are clearly beyond the narrow and limited terms of reference for this inquiry, failure to acknowledge them and take them into account could undermine the relevance and feasibility of findings and recommendations made by the Committee.

We recommend the following as invaluable resources to assist the Committee:

- (a) The report of the Victorian Parliamentary Committee inquiry into end of life choices, tabled on 9 June 2016.

(b) *Dying Well*², a highly regarded publication of the Grattan Institute, referred to extensively in the Victorian report and the evidence to the inquiry at a hearing³. Included in attachment 1 is the overview of *Dying Well*.

At the time of writing this submission, the Victorian report had only very recently been published and we need more time to give it the thorough consideration it deserves. However, we are convinced of the significance and relevance of its content and many of its findings and recommendations to the Tasmanian context. DwDTas made a submission and has reviewed and considered many of the submissions and the evidence provided at hearings.

We have reviewed its recommendations on an assisted dying legislative framework for Victoria. Although we agree with many of them, we find that some are not consistent with the Committee's own stated principles or the evidence it found most compelling (eg the Victorian Coroners Court evidence), and would have inadvertent cruel consequences. We will not go into detail here but would be prepared to provide more detail in response to any questions at a hearing or otherwise.

We recommend that the starting point for the Committee's deliberations should be consideration and adopting of the core values for end of life care proposed by the Victorian Parliamentary Inquiry into end of life choices on page 16:

Core values for end of life care

Every human life has value

Every individual person has inherent value.

Open discussion about death and dying should be encouraged and promoted

Death is an inevitable and natural part of life. It is human nature to fear death, however by acknowledging our own mortality through open discussions with health practitioners and family we can plan for our death.

People should be able to make informed choices about the end of their life

An adult with capacity has the right to self-determination. This is a fundamental democratic principle which should be respected. Information on end of life choices must be clear and accessible.

End of life care should be person-centred

The focus of medical treatment has shifted in recent times from a 'doctor knows best' mentality to patient-centred care. End of life care should be no different.

End of life care should address the needs of families and carers

The end of a person's life is a very stressful time for their families and carers, and can take a toll on their physical and mental health. End of life care services should extend to and provide assistance to families and carers during this difficult time.

² Available at <http://grattan.edu.au/wp-content/uploads/2014/09/815-dying-well.pdf>

³ http://www.parliament.vic.gov.au/images/stories/committees/SCLSI/Swerissen-FINAL-23_July_2015.pdf

Pain and suffering should be alleviated for those who are unwell

Not all treatment is beneficial for those at the end of life. Treatment provided to a 20-year-old may not be appropriate for an 80-year-old. The goal of end of life care should be to minimise a person's pain and suffering.

Palliative care is an invaluable, life-enhancing part of end of life care

Palliative care provides much needed pain relief for people during the end of their life, and provides comfort to their loved ones and carers. Palliative care often prolongs life.

High quality end of life care should be available to all people in all settings

People should be able to plan for death in their preferred setting.

Each person should be entitled to core rights in end of life care

All forms of discrimination in end of life care should be ended as far as possible, whether based on geographical location, physical condition, ethnicity or wealth.

Vulnerable people should be supported and protected

End of life care should focus on relieving pain and suffering. Safeguards need to be in place to ensure that vulnerable people are not pressured or coerced into making decisions that they do not want to.

The law should be coherent and transparent

Health practitioners and patients should be fully aware of their legal rights and responsibilities in end of life care.

The law should be followed and enforced

The purpose of end of life legislation should be to provide for end of life choices for patients and protection for doctors. Breaches of laws should be penalised appropriately.

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

The Victorian inquiry provides significant evidence of both the fact that palliative care and other medical treatment cannot relieve all suffering due to incurable and irreversible conditions. As the report notes: *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.* (p xxvii)

The report also demonstrates the substantial risks associated with ignoring these people and maintaining the cruel pretence their suffering does not exist. We draw the Committee's particular attention to the evidence to the Victorian inquiry about the risks of terrible suicides due to irreversible decline in health:

- *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.*

- Cases included in the report *“illustrate, as does the statistical evidence from the Coroner, that too many Victorians who experience an irreversible deterioration in their physical health, many of whom are elderly and frail, take drastic and brutal measures to end their lives”*.

The most impressive and harrowing of this evidence was given by the Victorian Coroners Court in a submission⁴ and evidence in a hearing⁵. The significance of that evidence and the impact it had on the Committee is addressed in detail in Chapters 6 and 7 of the report. What it shows above all is one of the serious risks associated with ignoring the needs of people with serious illness and suffering.

We don't know exactly what Tasmanian data would show, but it is reasonable to assume that the situation here is similar to that in Victoria. The Victorian Coroners Court research has provided the scientific data that adds to the anecdotal evidence we are only too well aware of, of lonely, too-early suicides by violent and unacceptable means, of *‘people who have invariably lived a long, loving life surrounded by family [who] die in circumstances of fear and isolation’* and of families, such as the Godfrey family, where the legal consequences of the criminal charge of assisting a suicide have been experienced as a reality or an ominous ongoing threat.

We also draw to your attention the excellent data and reports on palliative care outcomes published as part of the Palliative Care Outcomes Collaboration (PCOC) project at the University of Wollongong, funded by the Federal Government.⁶ This was not referred to in the Victorian report and we have relatively recently become aware of the project and reports. We refer you particularly to the “Trends in Patient Outcomes” report⁷ and the most recent national report for July to December 2015⁸. We welcome the chance to discuss them with you in some detail.

You will note on the PCOC website that there are specific State reports but not one for Tasmania. In a personal email exchange with the Director, Karen Quinsey, she advised: “We are currently working with the palliative care services in Tasmania to produce a report like the 5 other states, that would be available on the PCOC website. In the meantime, PCOC can provide information on Tasmania (i.e. combined across the services in Tasmania). There is a process where people can request information.” We recommend that the Committee seeks this information.

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

DwDTas has long had a very active program in support of end of life and advance care planning. DwDTas has arguably done more to promote end of life and advance care planning and to support and assist people to do their own planning than any other Tasmanian organisation.

⁴ [http://www.parliament.vic.gov.au/images/Submission_755 - Coroners Court of Victoria.pdf](http://www.parliament.vic.gov.au/images/Submission_755_-_Coroners_Court_of_Victoria.pdf)

⁵ [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)

⁶ Available at <http://ahsri.uow.edu.au/pcoc/index.html>

⁷ <http://ahsri.uow.edu.au/content/groups/public/@web/@chsd/@pcoc/documents/doc/uow207619.pdf>

⁸ <http://ahsri.uow.edu.au/content/groups/public/@web/@chsd/@pcoc/documents/doc/uow213151.pdf>

This has been driven by our Vice-President, Bill Godfrey, who at a hearing could provide you with valuable information and insights into the issue. His work has included:

- Development and maintenance of a detailed guide, *End-of-life planning: a summary guide to documenting your wishes and choosing an enduring guardian or person responsible*. A copy is available on our website at <http://dwdtas.org.au/guide-to-end-of-life-planning/>.
- Information sessions and longer workshops involving hundreds of participants.

A copy of the guide was sent to all Tasmanian MPs in September 2015 but we received very little response. We would like the opportunity to discuss with Committee members their response to receiving the guide, eg whether it went into category of ‘I’ll think about this some other time’ which is a common response to thinking about death. As the Victorian inquiry report notes: *As a community, our unwillingness to talk about dying is a major obstacle to advance care planning. Proper community education is essential to encouraging people to plan for their death. An overwhelming majority of people who create an advance care plan choose to receive palliative care at the end of life rather than life-prolonging measures.* (pxxv)

The Victorian report has extensive coverage, evidence, findings and recommendations on advance care planning which are very worth consideration by this Committee inquiry. Many recommendations reflect the same needs in Tasmania. In particular, we support the need for legal protection for the commitment to meet the wishes and instructions expressed in advance care directives. The report “*proposes introducing instructional health directives that include legally binding provisions and that cater for future medical conditions*” and recommends accordingly (Recommendation 48).

CONCLUSION

We wish the Committee well in its consideration of these important issues and look forward to being able to provide more information and assistance.

Overview: Hal Swerissen and Stephen Duckett, *DYING WELL*, Grattan Institute, September 2014 (page 2)

This report is about how, where and with whom we die. The baby boomers are growing old, and in the next 25 years the number of Australians who die each year will double. People want to die comfortably at home, supported by family and friends and effective services.

But dying in Australia is more institutionalised than in the rest of the world. Community and medical attitudes plus a lack of funds for formal community care mean that about half of Australians die in hospital, and about a third in residential care. Often they have impersonal, lingering and lonely deaths; many feel disempowered. Seventy per cent of people want to die at home, yet only about 14 per cent do so. People are twice as likely to die at home in countries such as New Zealand, the United States, Ireland and France.

Increasingly people die when they are old. They are also more likely than their forebears to know that they are going to die in the relatively near future. But we are not taking the opportunity to help people plan to die well. In the last year of life, many experience a disconnected, confusing and distressing array of services, interventions and relationships with health professionals. Many do not get enough palliative care.

Often, this is because people do not discuss the support they would like as they die. When asked, most people have clear preferences for the care they want at the end of their life. But rarely do we have open, systematic conversations that lead to effective end-of-life care plans.

A good death gives people dignity, choice and support to address their physical, personal, social and spiritual needs. This would happen more often with three reforms. 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. 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. Doubling the number of people who are able to die at home will cost \$237 million a year, but the same amount could be released from institutional care funding to pay for it.

Despite widespread assumptions about the cost of end-of-life care, only about \$5 billion a year is spent on the last year of life for older people in a health budget of \$100 billion. But only about \$100 million is spent on helping people to die at home. A change in focus will not save much, but will help more people to die well.

The voluntary euthanasia debate often clouds this issue. But voluntary euthanasia and assisted suicide are rare, even in jurisdictions that permit them. Instead, this report is about ensuring that when death inevitably comes for each of us, we die comfortably, in surroundings we would choose. We need the courage to promote mature discussions about a topic that many dislike, but that we cannot avoid.