



LEGISLATIVE ASSEMBLY
FOR THE AUSTRALIAN CAPITAL TERRITORY

SELECT COMMITTEE ON END OF LIFE CHOICES IN THE ACT

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Submission Cover Sheet

End of Life Choices in the ACT

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The Committee Secretary

Select Committee on End of Life Choices in the ACT

by email: LCommitteeEOLC@parliament.act.gov.au

Submission from Tibetan Buddhist Society of Canberra on End of Life Choices in the ACT

Summary:

“If we wish to die well, we must learn how to live well: Hoping for a peaceful death, we must cultivate peace in our mind, and in our way of life.”¹

His Holiness The Dalai Lama

In Buddhism, death is one of the most important event for a human being. The whole of life can be viewed as a preparation for death. Any consideration of death, and any measures to interfere with its course, need to be given our serious attention.

The Tibetan Buddhist Society of Canberra does not disagree with voluntary assisted dying when done correctly. The Society wants to emphasise that the Committee should consider death holistically and in addition to any inquiry into voluntary assisted dying, the Committee should also look at ways to help people die naturally and strengthen people’s ability to choose to die naturally rather than just focusing on one aspect, voluntary assisted dying. For balance, these two options must be considered together in any debate about a person’s ability to choose.

The Society recommends that:

- The Committee look at the barriers that prevent people choosing to die naturally such as-
 - issues concerning informed consent to medical treatment at the end of life; and
 - under investment in geriatric oncology expertise; and
 - barriers that prevent people accessing palliative care and advance care planning.

¹ His Holiness the Dalai Lama in Sogyal Rinpoche, *The Tibetan Book of Living and Dying*, 10th ed., (2002), Rider, London, p. ix.



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- The Committee should rule out voluntary assisted dying schemes that have unethical and inappropriate criteria. These schemes can contribute, over time, to an increasing number of deaths being the result of voluntary assisted dying and can lead to unethical outcomes. Inappropriate criteria include:
 - not having terminal illness as a criterion to access a voluntary assisted dying scheme which leads to the scheme being used to end the life of those with illnesses that the medical profession finds difficult to treat or explain (for example, dementia and mental illness)
- The Committee should look at ways to address the stigma and silence around death. As the Dalai Lama suggests, the Committee should look at ways to encourage people to “live well” with a peaceful mind in order that they are able to face death as a necessary part of life.
- Changing the law to help dying people to feel at ease with death by respecting a person’s wishes concerning the care of their body in the brief period after death clinical death (i.e. for up to 36 hours after clinical death). Currently, these decisions are dictated by the personal representative or the next of kin whose wishes may differ from those of the dying person.

To overcome opposition from the Federal Parliament, the ACT as a self-governing territory, needs to demonstrate that it can deal with the issue of voluntary assisted dying responsibly. This requires more than simply copying what Victoria has done. The ACT as a small progressive jurisdiction has an opportunity not just to follow what other jurisdictions have done, but to lead the world in creating a unique legal framework and providing services that allow a holistic view of death to be accommodated.

Detailed comments

The Tibetan Buddhist Society of Canberra submits the following comments on the Committee’s terms of reference:

- a) **Current practices utilised in the medical community to assist a person to exercise their preference in managing their end of life, including palliative care.**

According to Buddhism, there is continuity beyond clinical death of the most subtle aspect of a person’s mind. The process of death offers the opportunity for a person to realise this most subtle level of their mind.



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The *Tibetan Book of the Dead* says of this moment:²

*The nature of everything is open, empty and naked like the sky.
Luminous emptiness, without centre or circumference: the pure,
naked [inner most nature of mind] dawns.*

Anything that interferes with this realisation, such as the administration of drugs including sedatives and anaesthetics, can be harmful.

People should have the choice to die naturally and without the administration of substances at the point of death in order that these important experiences are not negatively affected.

Currently, the ACT has legislation that allows a person to make directions about the withholding or withdrawal of medical treatment.³ This allows a person to choose not to undergo medical treatment at the end of their life that they consider unnecessary so that they can focus on what is important to them, such as dying peacefully and naturally. Increased education for those at the end of life concerning this option should be explored.

The ACT should invest in having adequate geriatric oncology expertise and patient and practitioner education concerning informed consent for cancer treatment for the elderly. This will help people make the right choices at the end of their lives including the option to die naturally. As oncologist and columnist, Ranjana Srivastava, comments:⁴

For patients who are diagnosed with cancer when they are elderly or already have other significant health problems, this means understanding the crucial importance of truly shared decision-making. This starts with understanding the implications of a cancer diagnoses and asking for all the treatment options, ranging from the most aggressive to the least. As counterintuitive

²Cited in Sogyal Rinpoche, *The Tibetan Book of Living and Dying*, 10th ed., (2002), Rider, London

³ *Medical Treatment (Health Directions) Act 2006* (ACT).

⁴ Ranjana Srivastava, "To Treat or not to treat: find out what really matters to the patient", (24 January 2018), *The Guardian Australia* (retrieved at <https://www.theguardian.com/society/2018/jan/24/to-treat-or-not-to-treat-find-out-what-really-matters-to-the-patient>)



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as it might sound, a routine question should be: “What happens if I do nothing?”

Consideration of voluntary assisted dying also comes at a time when, resourcing for palliative care and end of life planning is under considerable pressure. For example, the Productivity Commission identifies in its draft report on the topic (the final report is pending) that meeting patients’ preferences about where they are cared for and where they die will require that governments “substantially increase the availability of community-based palliative care”.⁵ The Commission also emphasises the need for additional residential aged care staff trained in caring for people at end of life and an increase in the rate and quality of advance care planning. In respect of advance care planning the Commission comments:⁶

To ensure a real choice, people will often need to communicate their wishes ahead of time using an advance care plan (ACP). ACPs can include anything from a formal directive to a simple values statement, and have been shown to improve end-of-life experiences for patients, families and clinicians. Yet, despite efforts to promote advance care planning, less than 15 per cent of Australians have an ACP.

In research conducted by Palliative Care ACT and ACT Health on helping to support people to live and die well, it was concluded that carer fatigue, the patient’s rapid deterioration and carers/families not knowing the patient’s preferences are key reasons many people do not die in the place of their choosing.⁷ Support that would be most valued by patients, families and carers include information on available services, a helpline for advice or to organise support and information about the death and dying process. Barriers to people receiving the care they and their carers wish for include, on the one hand, a lack of understanding of palliative care among medical professionals and, on the other, an unwillingness on the part of medical professionals to discuss terminal or end-of-life treatment.

⁵ Productivity Commission, *Introducing Competition and Informed User Choice into Human Services Draft Report* (June 2017) p. 11 (full report is still to be released by the government) (retrieved at <https://www.pc.gov.au/inquiries/completed/human-services/reforms/draft/human-services-reforms-draft.pdf>).

⁶ Above reference, p. 12.

⁷ ACT Health and ACT Palliative Care, *Supporting People for Their End of Life Care Final Report* (5 September 2017) (retrieved at <https://www.pallcareact.org.au/wp-content/uploads/2017/11/End-of-Life-Final-Report-v1-2.pdf>)



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The ACT should invest in end-of life care that enables those at the end of their life to choose to die naturally and with dignity. Those at the end of their lives should not think that the only option for them is voluntary assisted dying. Therefore, any consideration of voluntary assisted dying needs to be looked at in a wider context.

b) ACT community view on the desirability of voluntary assisted dying being legislated in the ACT.

traditionally, Buddhism is against active euthanasia because suffering does not end at the point of clinical death but continues indefinitely until the karma that leads to the suffering is extinguished. Furthermore, human life is considered the most valuable resource in purifying the karma that leads to suffering and therefore should be preserved where possible. For example, the Dalai Lama:⁸

Your suffering is due to your own karma, and you have to bear the fruit of that karma anyway in this life or another, unless you can find some way of purifying it. In that case, it is considered to be better to experience karma in this life of a human where you have more abilities to bear it in a better way, than, for example, an animal who is helpless and can suffer even more because of that.

There is the assumption in any voluntary assisted dying scheme that suffering ends at clinical death. However, from the Buddhist philosophical perspective this is not clear.

A lot of the focus of the voluntary assisted dying debate is placed on the ability of a person to choose what is best for them.

The Society wants to emphasise that if any argument of freedom of choice is used to support voluntary assisted dying, the right for a person to die naturally also needs to be strengthened. The right for a person to die naturally can be strengthened by dealing with issues concerning informed consent to medical treatment at the end of life, investing in geriatric oncology expertise, and removing barriers that prevent people accessing palliative care and advance care planning.

⁸Cited in Sogyal Rinpoche, *The Tibetan Book of Living and Dying*, 10th ed., (2002), Rider, London at Appendix 2, p. 383.



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In addition, the Society recommends that the Committee look at ways to address the stigma and silence around death through increased education and dialogue. In research conducted by Palliative Care ACT and ACT Health it was noted that:⁹

Further education and awareness are required to link the general community to end of life support services. Education for the medical community is also required to encourage facilitating the cohesion between primary health, tertiary health and community support for patients end of life care. Building capacity for general and medical communities to enable end of life discussions may begin to break down the uncertainty and fear associated with death.

Death is an inevitable certainty of life. However, the culture of fear and denial of mortality prevents acceptance of, conversations on and pre-planning for death. The project respondents' fortitude in sharing their concerns and experiences with the death and end of life wishes of their loved ones may help to shift cultural attitudes to reframe death as part of contemplating and celebrating all phases of life.

c) Risks to individuals and the community associated with voluntary assisted dying and whether and how these can be managed.

Society sees a key risk to the community of voluntary assisted dying is that it is often used in isolation to deal with problems with death without dealing with wider issues. For example, issuing a prescription for a lethal dose of medication is made available without addressing a range of more complicated issues such as the stigma and fear of death in the community or increasing resourcing in palliative care.

Therefore, the criteria for voluntary assisted dying schemes, if adopted, need to be well-thought through and leave the option as a last resort, rather than a first port of call.

d) The applicability of voluntary assisted dying schemes operating in other jurisdictions to the ACT, particularly the Victorian scheme.

⁹ ACT Health and ACT Palliative Care, *Supporting People for Their End of Life Care* (5 September 2017) at p. 4 (retrieved at <https://www.pallcareact.org.au/wp-content/uploads/2017/11/End-of-Life-Final-Report-v1-2.pdf>)



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The Society is particularly concerned that the Committee does not recommend a voluntary assisted dying scheme that has inappropriate and unethical criteria that allows people to access it in ways, in circumstances, and in numbers, that would be damaging to the community.

Furthermore, under the Victorian scheme a person can access the voluntary assisted dying scheme when they have more than 6 months to live, or when they do not have “enduring and unbearable suffering”. There should be further research to the suitability of this criteria.

It must be noted that the Victorian legislation goes against the Parliamentary Committee’s recommendation that “enduring and unbearable suffering” should be a criterion.¹⁰

e) The impact of Federal legislation on the ACT determining its own policy on voluntary assisted dying and the process for achieving change.

The *Australian Capital Territory (Self-Government) Act 1988* prevents the ACT from making laws permitting voluntary assisted dying.¹¹ However, the ACT still has power to make changes in other areas that are still relevant to this issue. For example, the ACT could increase funding for palliative care or help to educate the public concerning advance care planning. Another option is to legislate to enable a person to make a binding order concerning care for their body in the 36 hours following clinical death (discussed below under paragraph (f)).

The process for achieving change in this area is for the ACT to demonstrate that it has considered the issue responsibly and has a robust and holistic policy in this area that accommodates a wide range of views in the community. It would be inappropriate for the ACT just to adopt another jurisdiction’s policy without carefully considering how each voice in our unique community can be appropriately accommodated.

f) Any other matter.

¹⁰ Parliament of Victoria, *Inquiry into end of Life Choices* final report (June 2016), p. xxviii (retrieved at https://www.parliament.vic.gov.au/images/stories/committees/SCLSI/EOL_Report/LSIC_58-05_Text_WEB.pdf)

¹¹ *Australian Capital Territory (Self-Government) Act 1988* (Cth), s 23 (1A).



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One area where the ACT can easily improve outcomes for those at the end-of-life is allowing a person to have more control over aspects of their burial that are important to them.

An important step is changing the law to help dying people to feel at ease with death by respecting their wishes concerning the care of their bodies in the brief period after clinical death (i.e. for up to 36 hours after clinical death). Currently, these decisions are dictated by the personal representative or the next of kin whose wishes may differ from those of the dying person. They can often lead to litigation.

In research conducted by Palliative Care ACT and ACT Health on helping to support people to live and die well, it was concluded carers/families not knowing the patient's preferences are key reasons many people do not die in the place of their choosing.¹² Often there can be disagreements in the family about how arrangements will be made following death and this can create stress for the family and for the dying person. Changing the law in this area would remove this uncertainty and allow the dying person to be in control.

The time following clinical death of a person is often full of significance. The Dalai Lama comments that, from a Buddhist perspective,¹³

The actual point of death is also when the most profound and beneficial inner experiences can come about. Through repeated acquaintance with the processes of death in meditation, an accomplished meditator can use his or her actual death to gain great spiritual realization. This is why experienced practitioners engage in meditative practices as they pass away. An indication of their attainment is that often their bodies do not begin to decay until long after they are clinically dead.

In order to support this process, it is important that the body of the dead person is not unnecessarily interfered with for example with invasive embalming procedures, injecting embalming fluids, or embalming procedures using chemical agents. Instead,

¹² ACT Health and ACT Palliative Care, *Supporting People for Their End of Life Care Final Report* (5 September 2017) (retrieved at <https://www.pallcareact.org.au/wp-content/uploads/2017/11/End-of-Life-Final-Report-v1-2.pdf>)

¹³ His Holiness the Dalai Lama in Sogyal Rinpoche, *The Tibetan Book of Living and Dying*, 10th ed., (2002), Rider, London, p. x.



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the dead person should be left for at least 36 hours in an unaltered state or moved to a closed casket. The laws of the ACT should be changed to support a dying person to fulfil their wishes in this regard.

The changes to the law can easily be made by amending Part 6 of the *Births, Deaths, and Marriages Registration Act 1997* (ACT) to allow a person to make a binding direction¹⁴ concerning the care of their body in the 36 hours following death to prevent their body being subjected to invasive embalming procedures, interventions, or the application of chemical agents. Rather than the direction placing positive obligations on a person to provide care for the body in a certain way, it would simply prevent the body being subjected to interventions. It might be extended to allow a person to direct that their body is not removed from the ACT and that they are buried or cremated and place a positive obligation that this occurs. The breach of a direction would be an offence. There could be exceptions for necessary post-mortem procedures undertaken by a doctor if the cause of death is unknown.

The Legislative Assembly of the ACT has the power to make such a law because it does not concern permitting euthanasia. Furthermore, it could be a way that the ACT is able to demonstrate its commitment to responsibly and holistically deal with matters that are important to the community.

¹⁴ A binding direction could be similar to an direction made under the *Medical Treatment (Health Directions) Act 2006* (ACT) but would cover the 36 hours following clinical death.



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ATTACHMENT 1: Forward by His Holiness the Dalai Lama in Sogyal Rinpoche, *The Tibetan Book of Living and Dying*, 10th ed., (2002), Rider, London, pp. ix-x.

Foreword **by His Holiness the Dalai Lama**

IN THIS TIMELY BOOK, Sogyal Rinpoche focuses on how to understand the true meaning of life, how to accept death, and how to help the dying, and the dead.

Death is a natural part of life, which we will all surely have to face sooner or later. To my mind, there are two ways we can deal with it while we are alive. We can either choose to ignore it or we can confront the prospect of our own death and, by thinking clearly about it, try to minimize the suffering that it can bring. However, in neither of these ways can we actually overcome it.

As a Buddhist, I view death as a normal process, a reality that I accept will occur as long as I remain in this earthly existence. Knowing that I cannot escape it, I see no point in worrying about it. I tend to think of death as being like changing your clothes when they are old and worn out, rather than as some final end. Yet death is unpredictable: We do not know when or how it will take place. So it is only sensible to take certain precautions before it actually happens.

Naturally, most of us would like to die a peaceful death, but it is also clear that we cannot hope to die peacefully if our lives have been full of violence, or if our minds have mostly been agitated by emotions like anger, attachment, or fear. So if we wish to die well, we must learn how to live well: Hoping for a peaceful death, we must cultivate peace in our mind, and in our way of life.

As you will read here, from the Buddhist point of view, the actual experience of death is very important. Although how or where we will be reborn is generally dependent on karmic forces, our state of mind at the time of death can influence the quality of our next rebirth. So at the moment of death, in spite of the great variety of karmas we have accumulated, if we make a special effort to generate a virtuous state of mind, we may strengthen and activate a virtuous karma, and so bring about a happy rebirth.



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The actual point of death is also when the most profound and beneficial inner experiences can come about. Through repeated acquaintance with the processes of death in meditation, an accomplished meditator can use his or her actual death to gain great spiritual realization. This is why experienced practitioners engage in meditative practices as they pass away. An indication of their attainment is that often their bodies do not begin to decay until long after they are clinically dead.

No less significant than preparing for our own death is helping others to die well. As a newborn baby each of us was helpless and, without the care and kindness we received then, we would not have survived. Because the dying also are unable to help themselves, we should relieve them of discomfort and anxiety, and assist them, as far as we can, to die with composure.

Here the most important point is to avoid anything which will cause the dying person's mind to become more disturbed than it may already be. Our prime aim in helping a dying person is to put them at ease, and there are many ways of doing this. A dying person who is familiar with spiritual practice may be encouraged and inspired if they are reminded of it, but even kindly reassurance on our part can engender a peaceful, relaxed attitude in the dying person's mind.

Death and Dying provide a meeting point between the Tibetan Buddhist and modern scientific traditions. I believe both have a great deal to contribute to each other on the level of understanding and of practical benefit. Sogyal Rinpoche is especially well placed to facilitate this meeting; having been born and brought up in the Tibetan tradition, he has received instructions from some of our greatest Lamas. Having also benefitted from a modern education and lived and worked as a teacher for many years in the West, he has become well acquainted with Western ways of thought.

This book offers readers not just a theoretical account of death and dying, but also practical measures for understanding, and for preparing themselves and others in a calm and fulfilling way.

June 2, 1992

The Dalai Lama