



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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Public Health Association of Australia submission on Inquiry into End of Life Choices in the ACT

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Contents

Preamble	3
The Public Health Association of Australia	3
Vision for a healthy population	3
Mission for the Public Health Association of Australia	3
Introduction	3
PHAA Response to the Inquiry Terms of Reference	4
Terminology.....	4
1. Current practices utilised in the medical community to assist a person to exercise their preference in managing the end of their life, including palliative care	4
2. ACT community views on the desirability of voluntary assisted dying being legalised in the ACT.....	5
3. Risks to individuals and the community associated with voluntary assisted dying and whether and how these can be managed.....	5
Equity.....	5
Pain and suffering.....	6
Competency.....	6
Safety.....	6
Beliefs about the sanctity of life.....	6
4. The applicability of voluntary assisted dying schemes operating in other jurisdictions to the ACT, particularly the Victorian scheme	7
5. The impact of Federal Legislation on the ACT determining its own policy on voluntary assisted dying and the process for achieving change	8
6. Any other related matter	9
Evidence-base.....	9
Conclusion	9
References	10

Preamble

The Public Health Association of Australia

The Public Health Association of Australia (PHAA) is recognised as the principal non-government organisation for public health in Australia working to promote the health and well-being of all Australians. It is the pre-eminent voice for the public's health in Australia. The PHAA works to ensure that the public's health is improved through sustained and determined efforts of the Board, the National Office, the State and Territory Branches, the Special Interest Groups and members.

The efforts of the PHAA are enhanced by our vision for a healthy Australia and by engaging with like-minded stakeholders in order to build coalitions of interest that influence public opinion, the media, political parties and governments.

Health is a human right, a vital resource for everyday life, and key factor in sustainability. Health equity and inequity do not exist in isolation from the conditions that underpin people's health. The health status of all people is impacted by the social, cultural, political, environmental and economic determinants of health. Specific focus on these determinants is necessary to reduce the unfair and unjust effects of conditions of living that cause poor health and disease. These determinants underpin the strategic direction of the Association.

All members of the Association are committed to better health outcomes based on these principles.

Vision for a healthy population

A healthy region, a healthy nation, healthy people: living in an equitable society underpinned by a well-functioning ecosystem and a healthy environment, improving and promoting health for all.

Mission for the Public Health Association of Australia

As the leading national peak body for public health representation and advocacy, to drive better health outcomes through increased knowledge, better access and equity, evidence informed policy and effective population-based practice in public health.

Introduction

PHAA welcomes the opportunity to provide input to the Inquiry into End of Life Choices in the Australian Capital Territory. The reduction of social and health inequities should be an over-arching goal of national policy and recognised as a key measure of our progress as a society. The Australian Government, in collaboration with the States/Territories, should outline a comprehensive national cross-government framework on promoting a healthy ecosystem and reducing social and health inequities. All public health activities and related government policy should be directed towards reducing social and health inequity nationally and, where possible, internationally.

PHAA Response to the Inquiry Terms of Reference

Terminology

This submission uses the following definitions:¹⁻³

Term	Definition
Autonomy	The capacity of a person to critically reflect upon and then attempt to accept or change one's desires, values and ideals
Euthanasia	For the purpose of relieving suffering, a person performs a lethal action with the intention of ending the life of another person
Voluntary euthanasia	Euthanasia is performed at the request of the person whose life is ended, and that person is competent
Competent	A person is competent if he or she is able to understand the nature and consequences of a decision, and can retain, evaluate and weigh relevant information in making that decision
Non-voluntary euthanasia	Euthanasia is performed and the person is non-competent
Involuntary euthanasia	Euthanasia is performed and the person is competent but has not expressed with wish to die or has expressed a wish that he or she does not die
Withholding or withdrawing life-sustaining treatment	Treatment that is necessary to keep a person alive is not provided or is stopped
Assisted suicide	A competent person dies after being provided by another with the means or knowledge to kill him or herself
Physician-assisted suicide	Assisted suicide where a doctor acts as the assistant
Palliative care	An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual

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

There are important practices and issues around someone managing the end of their life, and easing the death of someone with a terminal illness, which need to be considered prior to, and separate from, euthanasia and assisted dying. End of life communication, such as Advance Care Planning and Directives, helps patients to overcome communication barriers and provides a structure for ensuring their wishes are clearly outlined and respected. Multifocal interventions which may include lists of questions to be discussed, facilitated discussions and feedback, and group-based education as well as advance care planning may be the most successful in promoting end of life communication.⁴ Advanced care planning and documentation needs to be supported by legislation, such as is the case in the Australian Capital Territory. The legislative backing is important in supporting end of life choices such as who will make decisions on one's behalf if they are unable to communicate or incompetent, choices about what treatment is provided or withheld, choices about the location of dying, who might be present and any cultural or religious requests the person might have. Currently health professionals, patients and their loved ones lack the important protection of consistency of legislation regarding advance care planning across the states and territories.

Palliative care aims to help people live their life as fully and as comfortably as possible when living with a life-limiting or terminal illness. Palliative care identifies and treats symptoms which may be physical, emotional, spiritual or social, and is based on individual needs. The model is person-centred so that family, loved ones and carers can receive practical and emotional support.⁵ **Any legislation to legalise euthanasia should be accompanied by an additional commitment to improve access to palliative care.**

While euthanasia and assisted suicide have, until recently, been unlawful throughout Australia, a roundtable of doctors, lawyers, former politicians, and ethicists, both in favour and against legalisation, agreed that the practices still occur. In most Australian jurisdictions, current legislation allows doctors to withhold or withdraw life-sustaining treatment, thus allowing the underlying illness to take its course. Heavy sedation or pain relief may be prescribed even in the knowledge that a side effect of this treatment could be the shortening of the patient's life.⁶ The Australian Medical Association position statement clarifies that these measures do not constitute euthanasia or physician assisted suicide, because the intention is not to end life.

Withdrawing life-sustaining treatment is also conducted currently in Australia with patients who are not competent, for example in an irreversible coma, with the consent of their next of kin, emphasising the need for broader use of advance care plans.

2. ACT community views on the desirability of voluntary assisted dying being legalised in the ACT

PHAA has no comment on this issue

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

PHAA recognises that issues around end-of-life choices are contentious and difficult to resolve in a completely objective manner. Many people have personal experiences of, and cultural frameworks and beliefs about death which have informed their opinions, on both sides of the debate.

However, medical advances in the last century have increased longevity and changed end of life processes, while simultaneously, there has been a move within medical ethics towards patient centered care.⁷ Some of the important issues which need to be considered regarding legislation governing voluntary assisted dying are highlighted below.

Equity

The absence of legislation on end-of-life choices does not mean that some people do not make these choices.⁸ This has been recognised by medical practitioners and experts in Australia⁶ and internationally.^{9, 10} A lack of legislation does mean that there is inequity, with some people having the knowledge, power and opportunity to make and enact these choices, while others do not. Reasons such as disability or competence results in some people being in a position to end their life whilst others are not. In addition, whether or not the illness results in life being sustained by withdrawable treatment results in some people having the option to stop such treatment and expect the underlying disease to rapidly lead to death.

Pain and suffering

Euthanasia and assisted dying schemes usually have an element requiring the patient to be suffering unbearable and enduring pain. This has several implications. Firstly, the option is not available to those not suffering such pain. This is in contradiction with current practices of, for example, withdrawing life support from someone in a coma, who may not be suffering pain or experiencing severe distress.

Secondly, the option may not be available to those who are suffering such pain but are unable to clearly and repeatedly communicate that. Written requests especially, assume a certain level of ability and may exclude some patients who would otherwise meet the criteria.

Thirdly, the pain and suffering is usually focused on physical health rather than mental health. This may unfairly exclude people whose experiences of suffering are similar or worse than others with more demonstrable physical pain and ill-health.

Finally, there are large individual differences in the ability to cope with, or desire for, suffering. The subjective nature of this makes it difficult for fair and consistent decisions on who meets the criteria. The AMA position statement notes that there are some instances where it is difficult to achieve satisfactory relief from suffering, and that all patients have a right to receive such relief even where this may shorten their life.¹¹

It must be noted that there are limitations to the law in regards to end of life decision making, and that legislation cannot 'solve' the issue of suffering.

Competency

Another common feature of euthanasia and voluntary assisted dying schemes, is the requirement for the patient to actively request to die, and be competent to make that decision. When strict timeframes are imposed as well, patients whose competency declines as they near death, for example because of dementia, are unable to meet the criteria. This may have the effect of not respecting decisions made while competent, and also is in contradiction with the decisions currently made for patients who are not competent, for example withdrawing life-support from someone in a coma.

Safety

A study in New Zealand of people who were being prosecuted for having assisted a family member or loved one to die (which is not legal in New Zealand) emphasised the safety issues with unregulated assisted dying. Participants argued that in the absence of a regulated scheme, they were forced to use less safe methods to respect their loved one's wish to die. Exhaustion was evident and may have affected judgement, and the challenges involved in ensuring the act would be successful and painless, in the absence of medical expertise, were noted. Some participants had experienced unsuccessful attempts through starvation, which prolonged both pain and suffering.¹⁰

In jurisdictions where euthanasia or assisted suicide are legal, the technical mechanism for dying should be chosen to minimise the likelihood of accidental death. Mechanisms vary in ease of use for the dying. For instance, swallowing 100 pills may be physically difficult or impossible for someone in ill health, particularly if their appetite has been reduced by cancer treatment or a chronic illness such as COPD.

Beliefs about the sanctity of life

Australia is a diverse society, with people holding a wide range of religious and philosophical positions about the sanctity of human life and its ethical consequences. These views, which often contrast with each other, are nonetheless held in good faith. Members of the same family may not be uniform in their beliefs on this topic, and an individual's beliefs may change across their lifespan. In framing legislation for end of life management, it needs to be clear that it is the individual who is dying whose beliefs are primary in order to respect their autonomy.

Legislation, regardless of whether or not it permits euthanasia or assisted suicide, can be more or less accommodating of the diversity of ethical stances in Australian society. For instance, many jurisdictions with legislation allowing euthanasia or assisted suicide allow health professionals to not participate if they conscientiously object. This helps to acknowledge that autonomy in relation to euthanasia and assisted suicide incorporates interdependence with medical practitioners.

End of life care

Inequity exists in Australia in relation to people's access to appropriate palliative treatment and care. This is particularly true of access to high quality end of life care which may be affected by location (there is reduced or lack of access in regional and remote areas), education and knowledge of health professionals, and funding mechanisms which do not support holistic care. All possible action should be taken to ensure that a decision to participate in euthanasia is not driven by a lack of access to appropriate care.

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

Euthanasia or assisted dying schemes have been legislated in several places internationally including in the Netherlands in 2001, Belgium in 2002, Luxembourg in 2009,¹² and multiple states in the United States of America.⁷

It is an issue Australia has wrestled with many times since the first legislation was introduced in the Australian Capital Territory in 1993. Prior to the passing of the legislation in Victoria, there had been 51 bills introduced to various Australian parliaments without lasting success from 1993-2016. The majority of the bills proposed a model for law reform, 5 sought a referendum and 7 were Commonwealth bills attempting to remove the prohibition on territories legislating in this area following the overturning of the successful 1995 Northern Territory legislation.¹

The models proposed in bills introduced in Australian parliaments from 1993-2016 varied on method and eligibility elements such as whether the patient had to have a terminal illness; the nature of pain and suffering including the definition, degree, durability and cause; whether requests had to be current or could be made in advance; and oversight mechanisms. Most of the bills progressed as far as second reading, where the principle of the bill is debated, and there were no distinguishing features of those bills which progressed further.¹

The recently passed Victorian legislation allows for voluntary assisted dying through the administration of a specified substance. The guiding principles of the scheme are outlined in Section 5 and include: that every life has equal value and autonomy should be respected; assisted dying must not be presented as the only available option; patients need to be supported in the identification of the most appropriate path for them; open and clear communication; support for the patient; protection from abuse; and respect for culture, beliefs, values and personal characteristics. Eligibility is outlined in Section 9 and includes that patients must be a minimum age of 18 years; have capacity; be suffering from an incurable condition which is described as advanced, progressive and expected to cause death within six months or be diagnosed with a disease, condition or illness that is neurodegenerative and expected to cause death within weeks or months, not exceeding 12 months; and be suffering in a manner they consider to be intolerable. The scheme requires an initial request, a first assessment by an appropriately trained medical practitioner, a written declaration, and final request and review a minimum of 9 days after the initial request. When all criteria are satisfied, an assisted dying permit may be issued, and health practitioners who conscientiously object are protected and authorised to refuse to participate.¹³

PHAA submission on Inquiry into End of Life Choices in the ACT

The schemes operating in Belgium and the Netherlands are for euthanasia and are very similar to each other, with both allowing voluntary euthanasia - intentionally terminating life by someone other than the person concerned, at the latter's request. There must be a well-considered and repeated request, and the patient must have a medically futile condition of constant and unbearable physical or mental suffering that cannot be alleviated, resulting from a serious and incurable disorder caused by illness or accident. Two Doctors must agree, and if death is not imminent, a third independent physician must also consent, and allow a minimum of one month between the written request and the act.

Provisions are made for advance directives to allow for circumstances in which the patient is not conscious. This requires another two signatures and cannot be more than 5 years old. The Doctors must believe there is no reasonable alternative, and may conscientiously object.¹⁴

An amendment to the Belgian act in 2014 removes the previous age restriction over being at least 18 years old, but required that for minors, death must be imminent, the child must be capable of making the decision and needs to see a child psychiatrist or psychologist. This provision had only been used once from 2014-2017, with a 17 year old.¹⁴

There are concerns that the legislation supporting the scheme in Belgium contains practical and conceptual flaws which mean that illegal euthanasia practices still occur.¹⁴

The experience in overseas jurisdictions is that euthanasia and palliative care are able to work together rather than being contradictory practices, with their common principles of ensuring all available options have been considered, open communication, and respect for patient's wishes, autonomy, self-determination.¹⁵ The quality of hospice and palliative care in Oregon in the USA has improved since their physician assisted suicide scheme was introduced.⁷

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

The Euthanasia Laws Act 1997 is Federal Legislation which amends the Northern Territory (Self-Government) Act 1978, and the Australian Capital Territory (Self-Government) Act 1988, to remove the power of the Territory Governments to legislate in this area. This Commonwealth Act was introduced in response to the Northern Territory Rights of the Terminally Ill Act 1995 which had successfully passed through the Northern Territory Parliament, legalising euthanasia.

This unfair and inequitable Federal Legislation means the ACT and NT are discriminated against. The Territories should be treated equally with the States of Australia, and empowered to make their own laws on this topic, as with all others. The Act operationalises the Constitutional discrimination experienced by the Territories, where the Commonwealth has the power to override Territory legislation. The Territories lack Constitutional protection provided to the States, and experience discrimination in terms of their representation in the Senate, and weighting of votes in referenda.

The PHAA strongly opposes this discrimination and urges the ACT Government to lobby the Federal Government to remove the Euthanasia Laws Act 1997 as a matter of principle, regardless of whether the ACT Government subsequently legalises assisted dying or not. PHAA further urges the ACT Government to lobby for a Federal referendum to remove the Constitutional discrimination of the Territories.

6. Any other related matter

Evidence-base

The Palliative Care Australia position statement on euthanasia and physical assisted suicide notes that any public discussion and policy development on this issue should be informed by research.¹⁶ PHAA supports this position and further research on these issues.

Conclusion

PHAA supports the broad directions of the Inquiry and supports further discussion of these important issues. We are particularly keen that the following points are highlighted:

- further research and consideration of end of life choices is encouraged
- any legislation to legalise euthanasia or assisted dying should also include a commitment to improve access to palliative care and structured end of life communication such as advance care directives
- any legislation must include safeguards to protect both patients and health professionals

The PHAA appreciates the opportunity to make this submission and the opportunity to contribute to improving end of life choices in the ACT.

Please do not hesitate to contact me should you require additional information or have any queries in relation to this submission.


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