



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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COTA ACT Interim Submission
to the
Select Committee
on

Inquiry into End of Life Choices
in the ACT

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INTRODUCTION

COTA ACT is the peak organisation in the Australian Capital Territory concerned with all issues related to ageing. It is an independent, non-party political and non-religious organisation working to protect and promote the well-being, rights and interests of all older people in the ACT irrespective of socio-economic, ethnic, religious or cultural background.

‘End of life choices’ is a priority policy issue for COTA ACT and other COTAs nationally. COTAs in Victoria, NSW, South Australia, Northern Territory and Tasmania have been actively engaged in considerations by their respective state and territory governments on end of life choices and voluntary assisted dying legislation. In partnership with Palliative Care Australia, COTA Australia contributed to the update of the National Palliative Care Standards. COTA ACT is well placed to represent the needs and views of older people and work with the ACT Government in its deliberations about end of life choices.

This interim submission offers COTA ACT’s provisional views against the Inquiry’s Terms of Reference, pending a survey about older ACT residents’ views on end of life choices.

PROVISIONAL COMMENTS AGAINST TERMS OF REFERENCE

Older Australians are willing and able to take a high level of control over their lives, including the final phase of their livesⁱ. COTA ACT supports everyone’s right to a good death and advocates for the appropriate care services and support to be made available to help this occur. It is imperative that the wishes and beliefs of older peoples are respected and their right to make an informed choice about all options available regarding end of life be protected.

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

Palliative care is a critical component in ensuring a “good death”. While COTA ACT recognises that the existing palliative care services in ACT are of a high standard, there is significant unmet need for person-centred palliative care delivered in the home, hospital, hospice and residential aged care facilities. As the ACT population continues to age and an increasing number of people live out the final stages of their life with chronic, complex conditions, the demand for palliative care services will continue to increase.

To improve palliative care services in the ACT, COTA ACT supports the recommendations of the Health Care Consumers Association’s 2017 report: *Consumer and Carer Experiences and Expectations of Home based Palliative Care in the ACT specifically to:*

- ensure future funding and policy settings support home based palliative care services to consistently deliver person centred care, while meeting anticipated future increases in demand;
- establish a dedicated palliative care ward in the Canberra Hospital;
- explore options to respond to unmet need for hospice care for Canberra. While feedback on services provided by Clare Holland House is very positive, some people

have expressed a preference to access hospice services provided by a non-religious service provider;

- expand options for overnight respite for carers of people receiving home-based palliative care;
- train nursing and clinical staff in hospitals who are likely to care for people at end of life in palliative care and shared decision-making;
- introduce a care coordination approach at the Canberra and Calvary Public Hospitals for all people admitted to hospital while living with late-stage life-limiting illness; and
- continue to promote Advance Care planning among health care professionals and in the community.

COTA ACT is concerned that many dying elderly patients receive intensive 'life-saving' hospital treatment which, even if successful, simply results in temporarily prolonging an existence of negligible quality. UNSW Professor of Intensive Care Ken Hillman (*'A Good Life to the End'*) argues that hospital medical staff should not herd elderly patients who are soon-to-die into unnecessary operations and life-prolonging treatments without their wishes being taken into account. Instead, hospital doctors should offer alternative options that are much more sympathetic to the final wishes of most people facing the end of their lives.

COTA ACT urges support for the *Goal Setting and End of Life* project at the Canberra Hospital, which developed documentation for patients and clinicians to be used for patients at risk of dying in the next 12 months. The documentation and related new protocols were introduced in 2016, but changing the culture of this high-end acute care hospital from concentrating on saving people to supporting dying patients proved quite difficult. An education session with new doctors was planned for early this year, but did not eventuate because there were no educational resources. COTA ACT urges support for this culture-changing initiative to improve sustainability and improve outcomes for dying patients.

Anecdotally, there appears to be differing levels of misunderstanding, and sometimes fear, about end of life choices, particularly in people from culturally and linguistically diverse backgrounds. It is critical to develop a comprehensive understanding of the views and concerns of older Canberrans to inform any decisions about end of life policy, including people from culturally and linguistically diverse backgrounds, Aboriginal and Torres Strait Islanders and people with a disability.

COTA ACT recognises that palliative care is a national issue and notes that a national Palliative Care Strategy is being developed for consideration by COAG. We call on the ACT Government to advocate for the all governments to address the unmet need for palliative care, and in particular for:

- greater national consistency in the provision of palliative care services;
- investment in palliative care medicine specialists and nurses;
- national recognition of Advance Care Plans developed in the ACT; and
- improved access to palliative care in residential aged care facilities.

TOR 2 - ACT community views on the desirability of voluntary assisted dying being legislated in the ACT.

Older Australians have diverse, and often strong, views on end of life choices, including palliative care and voluntary assisted dying. These views can differ across the different age cohorts. Anecdotally, there appears to be differing levels of misunderstanding, and sometimes fear, about palliative care and end of life choices, particularly in people from culturally and linguistically diverse backgrounds.

It is critical to develop a comprehensive understanding of the views and concerns of older Canberrans to inform any decisions about end of life policy, including people from culturally and linguistically diverse backgrounds, Aboriginal and Torres Strait Islanders and people with a disability.

COTA ACT is well placed and willing to undertake a survey of older Canberrans on end of life choices, including voluntary assisted dying. COTA ACT can also conduct information sessions for older people on the full range end of life issues.

TOR 3 - The risks to individuals and the community associated with voluntary assisted dying, and whether and how these could be managed.

Risks to individuals

Possible risks would include harm to individuals if:

- A person is coerced by other individuals into seeking assisted dying.
 - This could be managed by criminalising coercion, and by public education of the proper purpose of voluntary assisted dying.
- A person is coerced by social attitudes into seeking assisted dying.
 - This could be managed by public education.
- A person who is mentally ill is allowed to seek assisted dying.
 - This could be managed by restricting the use of voluntary assisted dying to those who are not mentally ill.
- A person is denied life-prolonging treatment they have requested, leading them to request assisted dying.
 - This could be managed by ensuring that life-prolonging treatment is available to those that want it.
- A person is denied effective palliative care, leading them to request assisted dying
 - This could be managed by ensuring effective palliative care is available.
- A person is able to request voluntary assisted dying if they have a life prognosis of more than one year [whether this is a risk needs to be tested with the community].
 - This could be managed by restricting the use of voluntary assisted dying to those with a life prognosis of less than one year [but see comment on Victorian legislation below].

Risks to society

Possible risks include the moral debasement of society, if:

- An official policy emerges of encouraging assisted dying as a means of containing costs.
 - This could be managed by criminalising deliberate instances of this, and by public education.
- There is official tolerance of a social trend to devalue and disrespect older people, which indirectly encourages their suicide.
 - This could be managed by public education.
- Society allows people to choose to die when their agreed life prognosis is longer than one year. [This position needs to be tested against community views via survey].
 - If this risk is regarded as valid, it could be managed by restricting the use of voluntary assisted dying to those with a life prognosis of less than one year.

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

The Victorian legislation makes assisted dying available according to very tight eligibility criteria and subject to a demanding process of medical assessment, specialist opinion and independent review. The responsibility for initiating and re-confirming the application lies with the person, and there is an emphasis on establishing that the person has decision-making capacity and is acting freely.

It could be argued the Victorian legislation is too restrictive in that it allows voluntary assisted dying only for those people with a terminal prognosis of 6 months or less, or 12 months in the case of neuro-degenerative conditions.

Although s.18(4) of the legislation provides for an extended terminal prognosis period of 12 months for neuro-degenerative conditions, the operation of the decision-making capacity rule forbids the application of instructions contained in advance care plans. This would effectively prevent use of the legislation by most dementia sufferers. Also, the requirement for a prognosis of 12 months or less could cause some people with Parkinson's disease or MS to endure years of low quality bedridden existence before they became eligible.

The Victorian scheme also prejudices the fundamental question of whether the State generally has the right to limit personal freedom by requiring that voluntary assisted dying should only be legally available to individuals with terminal conditions with a time-limited life prognosis. The assumption that any other arrangement would be morally abhorrent needs to be tested against community views via survey.

It will be important to define the terminology referred to in any proposed legislation, e.g. Voluntary Assisted Dying as defined in the Voluntary Assisted Dying Bill (Victoria) 2017.

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

COTA ACT considers the ACT Government's inability to legislate on voluntary assisted dying significantly limits the scope of changes to end of life options available to older Canberrans. COTA ACT supports advocating the federal government to remove this obstacle.

CONCLUSION

It is imperative that the wishes and beliefs of older peoples are respected and their right to make an informed choice about all options available regarding end of life choices are recognized in legislation.

It is also important to work towards changing the social attitudes to ageing in our community. The fact that ageism exists in our community and in general, the older person is not valued must be taken into account. Negative sentiments regarding older people are often not openly expressed but will inform the debate so it is essential to bring them out into the open, confront them and try to change them.

COTA ACT would welcome the opportunity to meet with the Committee to discuss this important topic.

Jenny Mobbs, Executive Director, COTA ACT

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ⁱ 2013 COTA NSW 50+ Report with a focus on health and wellbeing accessed at <https://www.cotansw.com.au/MediaPDFs/2013-50-Plus-Report.pdf>