

Attention: The Principal Research Officer  
Select Committee on End of Life Choices  
Legislative Assembly  
Parliament House  
PERTH WA 6000



**By email:** [eolcc@parliament.wa.gov.au](mailto:eolcc@parliament.wa.gov.au)

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To the Joint Select Committee on End of Life Choices,

**Re: Inquiry into the need for laws in Western Australia to allow citizens to make informed decisions regarding their own end of life choices**

Cancer Council Western Australia (Cancer Council) commends the Parliament for encouraging public debate and accepting submissions on this important community issue.

Cancer Council is a non-government, not-for-profit cancer organisation that has no religious or political affiliations. Cancer Council has been involved in cancer research, patient support, cancer prevention and advocacy in Western Australia for 60 years. Cancer Council is a leading and active member of the cancer community, which comprises people affected by cancer, whether through a personal diagnosis or as family members, carers or health professionals.

Cancer Council's supporters, clients and staff come from all backgrounds and have diverse views on this challenging topic. As an advocate for cancer patients and their families, our responsibility is to ensure that these views are heard and respected, and that any future law reform reflects community sentiment and the best available evidence.

Rather than speak to each Term of Reference, we set out some key principles with a view to assisting the Joint Select Committee with its complex task:

1. Quality palliative care supports Western Australians with life limiting conditions (including cancer) to live, die and grieve well.
2. Advance Care Planning allows patients to make and communicate informed decisions about their health care and lifestyle in the future.
3. Any future legislation on end of life choices must have strong safeguards.
4. Equity demands that all Western Australians have access to palliative care, Advance Care Planning and any other future legislated options.

We thank the Joint Select Committee for facilitating this important community conversation. Should you require clarification of any matter raised in this submission, or would like to request additional information, please do not hesitate to contact me.

Yours sincerely,

Ashley Reid

Chief Executive Officer, Cancer Council Western Australia

## Palliative Care in Western Australia

The burden of cancer in the WA community continues to be high, with more than 12,000 residents diagnosed each year, and 4,000 deaths.<sup>1</sup> In 2015/16, 2,811 Western Australians died in hospital from a condition considered amenable to palliative care. Cancer was the principal diagnosis for 2,100 (around 60%) of these deaths.<sup>2</sup> This statistic does not include people who died at home or in residential aged care. Cancer Council emphasises that the Joint Select Committee's Inquiry must take into account this broader context.

Quality palliative care provides holistic support to people with a life limiting condition (including cancer) to live, die and grieve well. Our current state-wide model, The End of Life Framework<sup>3</sup> recognises that all patients, irrespective of their diagnosis or location, should receive high quality, safe, comprehensive and coordinated care at end of life. The Framework outlines best practice for palliative care at all stages of the patient's journey, but also identifies areas of improvement within the current health system. In summary, these include:

- an increasing demand for end of life care
- changing patterns of disease, with an increase in patients with complex health needs
- referral to Specialist Palliative Care teams, whilst recognising a need to build the capacity of all clinicians to incorporate palliative care into their practice
- lack of adequate coordination and continuity of care across health settings
- the number of patients who die in hospital despite a wish to die at home
- the challenges faced by rural and remote clinicians and communities
- the need for appropriate early referral to palliative care
- the need for greater community understanding of death, dying, loss, palliative care and the limits of medical interventions.

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<sup>1</sup> Threfall TJ, Thompson JR. *Cancer incidence and mortality in Western Australia*. Perth : Department of Health, Western Australia, 2014. Statistical Series Number 103.

<sup>2</sup> Government of Western Australia. ICD10 codes and separation due to death (Internal Document). Perth, Western Australia; 2017. Provided on 23 October 2017 by WA Cancer and Palliative Care Network on request from Cancer Council Western Australia.

<sup>3</sup> Government of Western Australia, Department of Health, WA Cancer and Palliative Care Network, *The End –of-Life Framework: A statewide model for the provision of comprehensive, coordinated care at end-of-life in Western Australia*. 2016. Available at: [http://ww2.health.wa.gov.au/~/\\_/media/Files/Corporate/general%20documents/End%20of%20Life/PDF/The-End-of-Life-Framework.ashx](http://ww2.health.wa.gov.au/~/_/media/Files/Corporate/general%20documents/End%20of%20Life/PDF/The-End-of-Life-Framework.ashx)

To meet these challenges and to ensure that quality palliative care is delivered at the right time, in the right place, to the right people, there must be an ongoing commitment and adequate funding. In our view, any future framework regarding end of life choices and care (and its implementation) must not erode continued strong investment to strengthen palliative care in WA. In the event that legislation is enacted in WA to permit voluntary assisted dying, access to quality palliative care will continue to be a priority for all patients with a life limiting condition.

### **Advance Care Planning in Western Australia**

The End of Life Framework emphasises the importance, at any stage of life, of individuals discussing their preferences through Advance Care Planning. The Framework explains that, “engaging in open and honest conversations, discussing care preferences and acknowledging the limitations of treatment will assist us to view death and dying as part of life and allow us to live well and die well.” In this way, palliative care incorporates and promotes Advance Care Planning to assist patients to make informed decisions about their future care, treatment and lifestyle, and to share these with trusted persons. .

Advance Care Planning is considered to be an ongoing discussion and process between patients and their families and health care professionals. If these discussions and plans are formalised in writing, they may involve the use of these instruments in WA: Advance Health Directives, Enduring Power of Attorney and Enduring Power of Guardianship. The legal framework for these is found in the *Guardianship and Administration Act 1990* (WA). An Advance Care Plan may also be used to record and communicate wishes about end of life care and arrangements, but is not legally binding.

The framework for Advance Care Directives (including Advance Health Directives and the appointment of substitute decision makers for healthcare decisions) was introduced in Western Australia in 2008 by way of legislative amendment following extensive public consultation. Although this framework cannot guarantee quality end of life care, it is valuable legislation that underpins a comprehensive approach to informed decision making at end of life.

In the decade following its implementation, we have been able to informally evaluate the impact of Advance Care Planning in clinical practice. As Advance Care Planning is a continuous and dynamic process, it is difficult to define outcomes and measure them

objectively. This is an area that would benefit from targeted research. In our experience, Advance Care Planning within the Residential Aged Care Sector has become routinely incorporated. In acute care settings, responsibility for initiating Advance Care Planning often falls to social workers and may at times lack an integrated and holistic approach.

A significant barrier to more widespread adoption is a gap in knowledge and understanding among health care professionals about Advance Care Planning. Ideally, all clinicians should incorporate Advance Care Planning into their practice. General practitioners are especially well placed to initiate a discussion about Advance Care Planning at an early stage. At the level of patients, there may be confusion about the different options for substitute decision making and the common law requirements for a valid and enforceable Advance Health Directive.

These observations are broadly consistent with a study in the peer-reviewed literature which found that the uptake of advance directives in South Australia has been low.<sup>4</sup> Instruments for substituted decision making about financial matters, such as Powers of Attorney, were more likely to be used than those for health care decisions. The authors noted that in Australia, barriers to effective completion of advance directives include poor understanding and application of the different forms.

Cancer Council's view is that the existing Advance Care Planning framework is an essential component of end of life care and must be retained and optimised, irrespective of any other legislative options that may become available in the future. Under no circumstances should Advance Care Directives be capable of providing legal authority for assisted dying in an incompetent patient.<sup>5</sup>

There is a compelling case for investment in a state-wide health promotion strategy to promote public awareness, health professional education and consumer engagement to increase the uptake of Advance Care Planning. In this respect, important work is being undertaken by the WA Cancer and Palliative Care Network and Palliative Care WA, but is still in its infancy. A coordinated approach including the Department, not-for-profit

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<sup>4</sup> Bradley LS, Woodman RJ, Tleman JJ, Phillips PA. Use of advance directives by South Australians: results from the Health Omnibus Survey Spring 2012. October 2014. *MJA*; 201(8): 467-469.

<sup>5</sup> For detailed discussion on this issue, we refer to State of Victoria, Department of Health and Human Services, July 2017. Ministerial Advisory Panel on Voluntary Assisted Dying: Final Report. Pages 61-63. Available at: <https://www2.health.vic.gov.au/about/publications/researchandreports/ministerial-advisory-panel-on-voluntary-assisted-dying-final-report>

organisations and peak bodies would maximise engagement with health professionals and consumers. Better implementation of existing laws will ensure that more Western Australians at all stages of life are able to make informed decisions about treatment in the case of future incapacity, and about end of life care options.

### **Safeguards for any Future Legislation**

Any future legislation to, 'allow citizens to make informed decisions regarding their own end of life choices' must have advantages beyond the existing framework in the *Guardianship and Administration Act 1990* (WA). Cancer Council would support reforms intended to simplify and clarify the framework, so as to enable it to be implemented more effectively.

Cancer Council takes no organisational position on whether legislation should be proposed in WA specifically to enable voluntary assisted dying. It is clear, however, that cancer patients and their families will be disproportionately affected by any such law reform. In countries that have legislated for assisted dying in some form, terminal cancer patients have comprised the largest group of patients to access some form of assisted dying<sup>6</sup>.

Should the community support legislation to give effect to voluntary assisted dying, it should permit people to obtain assistance to die in exceptional circumstances where palliative care cannot provide the relief needed to address pain and suffering at end of life. Such a choice, if legislated, should be available only when the patient, with capacity and fully informed of the options for managing their suffering, decides voluntarily that their suffering cannot be relieved in a manner that they deem tolerable.

There are legal and practical safeguards that can be included to minimise risks, but it would serve no purpose to outline them in this submission. If the issue becomes tangible rather than hypothetical and is proposed as legislation, there will be an opportunity to consider its drafting in detail.

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<sup>6</sup> Emanuel, E, Onwuteaka-Philipsen, B, Urwin, J, and Cohen, J (2016) 'Attitudes and Practices of Euthanasia and Physician-Assisted Suicide in the United States, Canada, and Europe' *JAMA* 2016;316 (1):79-90.

## **Equitable Access to End-of-Life Choices**

Cancer Council emphasises that any legislation concerning end of life choices or voluntary assisted dying must not undermine the principle of equitable access to health care. This means that all end of life choices and care options (including access to Palliative Care) must be available to all Western Australians, including people in regional and rural areas, people with less common illnesses, people from culturally and linguistically diverse communities, Aboriginal and Torres Strait Islander people, people with greater health literacy needs, and people with limited financial resources.

Cancer Council supports increased investment in health promotion strategies to better enable Aboriginal people and people from culturally and linguistically diverse backgrounds to take advantage of existing Advance Care Planning.<sup>7</sup>

Further, no person should receive less favourable treatment because he or she has made a particular choice about end of life.

## **Conclusion**

The issue of voluntary assisted dying by its nature is one that invokes ethical and moral division. As an independent organisation with supporters who hold a range of views and beliefs, Cancer Council believes that these views must be valued and shared in robust, respectful community debate. Although Cancer Council takes no position on the desirability or otherwise of legislation to give effect to voluntary assisted dying, we urge the Joint Select Committee to consider in its examination the broader context. As outlined in this submission, this includes the pressing need to:

- strengthen and improve access to palliative care in WA;
- better promote Advance Care Planning among the general public, patients and health professionals; and
- ensure that all Western Australians, including Aboriginal people, people from culturally and linguistically backgrounds and people in regional and remote areas, can take advantage of the end of life choices that are available.

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<sup>7</sup> See, for example, Sinclair C, Williams G, Knight A, Auret K. A public health approach to promoting advance care planning to Aboriginal people in regional communities. *Aust J Rural Health* 2014; 22: 23-28.

Should the community and government support law reform to give effect to voluntary assisted dying, Cancer Council stresses the need for strong safeguards and an evidence-based approach, drawing on the outcomes of such legislation in other countries,<sup>8</sup> as reported in the peer-reviewed literature.

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<sup>8</sup> See, White B & Willmott L. How should Australia regulate voluntary euthanasia and assisted suicide? *Journal of Law and Medicine*. 2012; 20: 410-438 for an examination of regulatory approaches in other countries.