



**LEGISLATIVE ASSEMBLY**  
FOR THE AUSTRALIAN CAPITAL TERRITORY

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**SELECT COMMITTEE ON END OF LIFE CHOICES IN THE ACT**

Ms Bec Cody MLA (Chair), Mrs Vicki Dunne MLA (Deputy Chair), Ms Tara Cheyne MLA,  
Mrs Elizabeth Kikkert MLA, Ms Caroline Le Couteur MLA.

## Submission Cover Sheet

### End of Life Choices in the ACT

**Submission Number: 451**

**Date Authorised for Publication: 19/4/18**



23 March 2018

Andrew Snedden  
Committee Secretary  
Select Committee on End of Life Choices in the ACT  
GPO Box 1020  
CANBERRA ACT 2601

Dear Mr Snedden,

**Re: Submission to Select Committee Inquiry on End of Life Choices in the ACT**

Thank you for the opportunity to make a Submission to the Select Committee Inquiry on End of Life Choices in the ACT.

Cancer Council ACT (CFACT) is a non-profit organisation involved in providing support to people with cancer in the ACT and surrounding region through the provision of information and supportive care, prevention campaigns, advocacy and research.

All end of life choices are complex and include legal, ethical, health and practical considerations and CFACT supports the broad terms of reference for the Inquiry. The possible inclusion of voluntary assisted dying as an end of life choice adds to the complexity.

CFACT would wish to ensure that if a legislative decision is made regarding assisted dying as an end of life choice, that an individual has access to the very best information regarding all choices, and equitable access to the best end of life care possible, to assist them to make fully-informed decisions about their care and management. This is the basis of our Submission.

If you have any questions about our Submission, please do not hesitate to contact CEO, Sandra Turner, Cancer Council ACT on (02) [REDACTED] or email [REDACTED]

Yours sincerely,

[REDACTED SIGNATURE]  
Sandra Turner  
**Chief Executive Officer**

And on behalf of:  
Christine Brill, President of the Board  
Dr Paul Craft, Board Director

Enc: Cancer Council ACT Submission to Select Committee Inquiry on End of Life Choices in the ACT

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*A member of Cancer Council Australia*

## **Cancer Council ACT Submission to the Select Committee Inquiry on End of Life Choices in the ACT**

Cancer Council ACT (CFACT) thanks the Legislative Assembly for the ACT Select Committee Inquiry on End of Life Choices in the ACT for the opportunity to provide a submission.

This Submission has considered both the Cancer Council Victoria Submission into the Victorian Inquiry into End of Life Choices as well as the AMA Position Statement (2016) – specifically, ‘Good quality end of life care and the relief of pain and suffering’ in the writing of this document.

### **Context for CFACT’s Submission**

CFACT is a non-profit cancer charity that has had a presence in the ACT for over 40 years and is involved in patient and family support, cancer prevention and cancer research.

Many people in the ACT are faced with a diagnosis of cancer every year. It is estimated that close to 2300 people in the ACT will be diagnosed with cancer in 2018 and almost 800 with cancer will die.<sup>1</sup>

Following a diagnosis of cancer, there are many challenging issues to consider, including decisions regarding treatment, where treatment will be managed, costs of treatment and to the family unit, outcomes, possible remission and disease progression and subsequent management of end of life.

Research into assisted dying in other countries suggests the main group of patients seeking access to some form of assisted dying have cancer.<sup>2</sup>

End of life choices are complex and considerations include legal, ethical, health and practical points of reference and CFACT supports the broad terms of reference for the Inquiry.

It is acknowledged that in a small number of cases not all pain and suffering at end of life can be relieved in a manner the person deems tolerable, even with high quality palliative care; it is in this instance that CFACT understands any future legislation would make assisted dying an option.

It is not CFACT’s role to support or oppose assisted dying legislation, rather to recognise the diversity of stakeholder views and choices in relation to assisted dying, encourage analysis and open discussion and respect the rights of individuals and organisations to have such views.

CFACT would wish to ensure that whatever legislative decision is made, an individual faced with an end of life decision has access to the very best information and end of life care possible to assist them to make fully-informed decisions about their care and management at this time. This is the basis of this Submission.

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<sup>1</sup> Cancer Australia Website: [https://canceraustralia.gov.au/affected-cancer/what-cancer/cancer-australia-statistics \(as a percentage of national population\)](https://canceraustralia.gov.au/affected-cancer/what-cancer/cancer-australia-statistics (as a percentage of national population)).

<sup>2</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.

## **Main points for consideration:**

### **High-quality end of life care for all – palliative care**

Palliative care is an approach that improves the quality of life of patients and their families facing the problems 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.<sup>3</sup>

Palliative care can be provided in the hospital setting, in hospice care, or in the home. The care provided is usually provided by a multidisciplinary team including a palliative care physician and specially trained nursing staff.

For most patients near the end of life, pain and suffering can be alleviated through the initiation of good palliative care, where symptoms can be relieved, and quality of life left can be improved. This is sometimes difficult to achieve for some cancer patients even with excellent end of life care. Cancer is the most frequently recorded principal diagnosis for palliative care-related hospital separations.<sup>4</sup>

### ***Barriers to Palliative Care***

Palliative care must be accessible to all on an equitable basis, regardless of a person's social, cultural or economic circumstances.

The ACT is in a unique position when it comes to palliative care in that almost a third of patients treated for cancer come from outlying, regional NSW areas, not just the ACT. This puts additional pressure on the current services available to patients.

The ACT needs to be able to meet the needs of the region when it comes to the provision of good palliative care, and in a timely manner, so that individuals have access when required. Depending on the disease and the individual circumstances, palliative care can be required up to several weeks or even months prior to a person's end of life expectancy.

Early referral to palliative care for persons affected by advanced cancer has been shown in randomised trials to improve outcomes such as quality of life and even survival.<sup>5</sup> Integration of palliative care into mainstream services is thus crucial. Education and support to patients and families to understand the role palliative care plays in the management of their disease as it progresses is crucial as part of a comprehensive treatment plan.

Sufficient community and consultative palliative care must be available to meet demand. Without this, patients may not receive palliative care at all, or at best, limited care that does not adequately alleviate pain and suffering. Building capacity needs to be a priority in the ACT and may be assisted by increased utilisation of palliative care nurses, improved general practitioner education and support, and improved utilisation of volunteers.

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<sup>3</sup> WHO definition of Palliative Care: <http://www.who.int/cancer/palliative/definition/en/>

<sup>4</sup> AIHW 2014c. Palliative care services in Australia 2014. Cat. no. HWI 128. Canberra: AIHW, in: Australian Institute of Health and Welfare: AIHW 2017 Cancer Report, p 38.

<sup>5</sup> Early palliative care for patients with metastatic non-small-cell lung cancer. Temel JS et al. N Engl J Med. 363(8):733-42. 2010

In-hospital and community palliative care services need to be fully serviced and available 24/7 for those that require support. In the ACT, access to palliative care support after working hours can be limited and does affect the care of patients.

The provision of an holistic approach to palliative care can assist in preventing the desire for someone to access end of life assistance.

### **Planning for end of life care**

Most people rely on support from family, friends and carers, as well as health care professionals to provide support and advice along the way to assist them to make informed decisions about their care and ultimately end of life and death.

General practitioners play an important role, not only in caring for the patient in the physical sense, but to assist the patient and family in broader decision making about a range of issues including other supportive services such as respite care, home support, etc.

General practitioners and other professionals can also assist people with advance care planning, which is a process that enables an individual to consider what is important to them as they become less able to make and communicate their own care decisions. It reflects one's beliefs, values, goals and preferences and outlines desired care at end of life. It is also a way to remain involved in one's own medical decisions beyond the point at which decision-making capacity is lost.

The ACT has a range of options for people to plan for their end of life care, including Enduring Power of Attorney, Advance Care Planning Statement of Choices and a Health Direction.

Community education regarding the importance of having these documents completed and full and frank discussion with appropriately training professionals (e.g. clinicians, social workers) early in the cancer treatment pathway, will assist the patient to make appropriate decisions for care as they get closer to end of life. It is best these documents are completed early in the process, especially whilst the patient is still able to make competent decisions and prior to referral to palliative care services.

***If assisted dying legislation is introduced, the following elements are most important.***

### **Information and support for patients and their carers**

Any person who requests assisted dying, if such a scheme is introduced, must be provided with the necessary information and support to make such a decision. The decision must be fully informed and available only to people with the decision-making capacity to make such a request.

End of life discussions relating to assisted dying would need to consider the implications for the individual, family and friends, including the right for those left behind to have the same access to services such as bereavement counselling. The individual's decision requires a compassionate response and support for them and their family.

Any assisted dying legislation must consider those in the community that are vulnerable, including those with compromised decision-making capacity.

Assisted dying must not become the 'expected norm' for a person with end stage cancer or any other terminal disease.

### **Education, training and support for health professionals**

If an assisted dying scheme is introduced, health professionals would need tailored education and training on the scheme to ensure understanding of and compliance with the legislation and provision of accurate and appropriate information to people seeking assisted dying.

There are significant legal, moral and ethical issues involved. The specific clinicians involved would need to be able to voice a conscientious objection to the assisted dying process without prejudice.

### **Oversight and monitoring**

Any legislation on assisted dying would need to have clear information and data collection and reporting obligations at each stage of the assisted dying request and administration process to ensure effective and timely oversight, monitoring and evaluation of the scheme.

Appropriate safeguards would need to be ensured, including strict drug control measures.

Death notification should also capture assisted dying as a cause of death in some manner for data collection purposes, including cancer registry information and research purposes.

### **Cross-border and residency issues**

A significant number of people travel into the ACT from surrounding NSW for health care. This care includes cancer treatment and palliative care. Legislation around assisted dying would need to accommodate cross border issues in medical care and avoid a situation of conflicting arrangements and legal implications across the two jurisdictions.

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