Submission Cover Sheet

End of Life Choices in the ACT

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THE LEGISLATIVE ASSEMBLY FOR
THE AUSTRALIAN CAPITAL TERRITORY

GOVERNMENT SUBMISSION TO
Select Committee on End of Life Choices in the ACT

Presented by
ACT Government
Introduction

The establishment of the Select Committee provides the ACT Community with an opportunity to discuss the important social policy and legal considerations relating to end of life choices in the ACT.

Currently, the ACT cannot legislate for voluntary assisted dying due to law making restrictions placed on the ACT Legislative Assembly by the Commonwealth Parliament. The Government is strongly of the view that regardless of one’s views on voluntary assisted dying, Canberrans should be afforded equality under the law to legislate on this issue if the community desires. Given this, the Government argues that these restrictions should be removed as a priority to give people in the ACT the right to decide if voluntary assisted dying laws should be introduced in the ACT.

This submission outlines the current legal framework on end of life choices in the ACT, and current practices surrounding end of life and palliative care in the ACT. This Submission does not hypothesise on possible voluntary assisted dying schemes that could be appropriate for the ACT. This is a matter for further consultation with the ACT community and consideration if the prohibitive Commonwealth laws are repealed. Repeal of these laws would give members of the Legislative Assembly an opportunity to examine all the available information and, as legislators, represent and reflect the ACT community’s views.

Background

In 1995 the Northern Territory enacted the Rights of the Terminally Ill Act 1995 (NT) that established a framework for a person with a life limiting illness in the Northern Territory to request assistance from a medically qualified person to voluntarily terminate his or her life in a humane manner.

In response to this law, and utilising its power under Section 122 of the Commonwealth Constitution, the Commonwealth Parliament passed the Euthanasia Laws Act 1997 (Cth) (“the Commonwealth Euthanasia Act”, also known as the “Andrews Bill”), which precluded both the NT and ACT legislatures from making laws relating to euthanasia. The Act inserted section 23(1A) into the Australian Capital Territory (Self-government Act) 1988 (Cth) (“Self-government Act”) which provides:

    The Assembly has no power to make laws permitting or having the effect of permitting (whether subject to conditions or not) the form of intentional killing of another called euthanasia (which includes mercy killing) or the assisting of a person to terminate his or her life.

Since the passage of the Commonwealth Euthanasia Act, no jurisdiction in Australia had legislated in respect to voluntary assisted dying until 29 November 2017, when the Victorian Parliament passed the Voluntary Assisted Dying Act 2017 (Vic) (“Victorian Act”).
The passage of the Victorian Act was preceded by much public consultation and debate, including consideration of this issue by the Victorian Parliament’s Legislative Council Legal and Social Issues Committee, which produced a comprehensive Final Report\(^1\). Subsequently, the Victorian Ministerial Advisory Panel on Voluntary Assisted Dying released an in-depth expert report.\(^2\) The extent of consultation, research and discussion on the issues provides a valuable source of information for the ACT to consider if the prohibition on making euthanasia laws is removed.

**Inability of the ACT to legislate on end of life choices**

Section 122 of the Australian Constitution enables the Commonwealth Parliament to override any Territory law, which it did by enacting the Commonwealth Euthanasia Act. This legislation precludes the Legislative Assembly from passing a voluntary assisted dying scheme similar to the Victorian Act.

For the ACT to be able to legislate in relation to an assisted dying scheme similar to Victoria’s, the Commonwealth Parliament must first repeal s23(1A) of the Self-government Act and Schedule 2 to the Commonwealth Euthanasia Act.

It is the position of the ACT Government that limitation on the Legislative Assembly in this area is a restriction of democratic freedoms for residents in the ACT, which should be addressed as a priority.

**Current legal framework concerning end of life choices in the ACT**

There is no law in the ACT to provide for voluntary assisted dying, due to the Constitutional limitation outlined above.

There are several laws, policies and practices relating to end of life decisions and actions. A list of these is provided in Appendix A and discussed further below.

**Applicable offences**

The law in the ACT proscribes doctors from acting on a request from a patient to voluntarily end their life. A range of criminal offences potentially apply to health professionals (and others) who assist with voluntary dying, including the following offences under the *Crimes Act 1900* (ACT):

- Murder (s12)
- Manslaughter (s15)
- Suicide – aiding etc (s17)

The offence of aiding suicide (s17), provides that a person who aids or abets the suicide or attempted suicide of another person is guilty of an offence punishable by imprisonment for 10 years. In light of the Commonwealth Euthanasia Act, these offences cannot be displaced to allow for end of life choices.


Other relevant laws in the ACT

Palliative Care

ACT law allows a doctor to provide palliative care to ease a person's pain and suffering. It is generally recognised that this is permissible even where it has the effect of hastening the person's death, providing the intent was not to do so, but rather to ease pain and suffering. An outline of palliative care practices in the ACT is noted below.

The Medicines, Poisons and Therapeutic Goods Act 2008 (ACT) ("MPTG Act") governs the prescribing of medicines in the ACT that may be used for voluntary assisted dying. The ACT adopts Commonwealth scheduling of medicines and poisons contained in the Poisons Standard under the MPTG Act. Controlled medicines are medicines listed under schedule 8 of the Commonwealth Poisons Standard. The prescribing and supply of controlled medicines are subject to increased regulation throughout Australia due to their potential for harm such as abuse, misuse, dependence or diversion. Controlled medicines include opioid painkillers such as morphine and oxycodone, which are used extensively in palliative care.

In the ACT, a prescriber who wishes to prescribe a controlled medicine must seek approval from the Chief Health Officer where prescribing is for greater than two months or the person is drug dependent. Applications for approval are considered against the Controlled Medicines Prescribing Standards ("Prescribing Standards"), which is a notifiable instrument approved by the Chief Health Officer under the MPTG Act.

Category 2 of the Prescribing Standards enables the prescribing of opioid controlled medicines to treat a person with pain directly attributable to active malignancy or life limiting disease. There are no provisions in the MPTG Act to enable the prescribing of schedule 9 (prohibited) substances to patients, other than for research and education purposes in defined circumstances.

Further clarity around legal liability for the actions of medical professionals in the ACT in relation to end of life decisions is provided by the Director of Public Prosecutions Direction 2006 (No 2) (ACT)³ which directs the Director of Public Prosecutions not to prosecute in certain circumstances:

...where the death of a person occurs following a health professional:

- withdrawing or withholding treatment of the person in good faith in accordance with the written direction or record of a direction of the person or representative of the person appointed in accordance with the Medical Treatment Act 1994;⁴
- withdrawing or withholding treatment of the person in good faith in accordance with a written request or record of a request by the donee of a power of attorney given by the person; or

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¹ Notifiable Instrument NI2006-356 issued under s 20, Director of Public Prosecutions Act 1990 (ACT).
² A reference to the Medical Treatment Act 1994 (ACT) includes a reference to the Medical Treatment (Health Directions) Act 2006 (ACT) by virtue of the Legislation Act 2001 (ACT) s102(1)(a).
- providing pain relief in good faith to a person diagnosed as being in the terminal phase of a terminal illness where an incidental effect of the pain relief appears to have been the hastening of death;

and the death is attributed (in whole or part) to such withdrawal or withholding of treatment or provision of pain relief, the Director of Public Prosecutions shall not, by reason only of such withdrawal or withholding of treatment or provision of pain relief (regardless of when it occurs), proceed with a prosecution of the health professional.

Health Directions

ACT law provides that competent adults may also end their lives by refusing a medical intervention or substance. Competent adults in the ACT can make “Health Directions”, to express their choices relating to end of life decisions. Section 7 of the Medical Treatment (Health Directions) Act 2006 (ACT) (“Medical Treatment (HD) Act”) provides:

(1) An adult can make a direction (a health direction) to refuse, or require the withdrawal of, medical treatment generally or a particular kind of medical treatment.

...(3) However, a health direction cannot be made by—
(a) a person for whom a guardian is appointed under the Guardianship and Management of Property Act 1991; or
(b) anyone else who has impaired decision-making capacity.

The relevant Explanatory Statement states that this section “protects a health professional or a person acting under the direction of the health professional, from civil or criminal liability, for a decision to act under a health direction”.

This protection is given where two elements are met. One is that the health professional makes a decision that he or she believes on reasonable grounds complies with the Medical Treatment (HD) Act. The second is that the health professional or other person acted honestly and in reliance on that decision, and withholds or withdraws medical treatment from a person.

Section 18 of the Medical Treatment (HD) Act provides that if a person has made a health direction but then loses their decision-making capacity and a guardian or health attorney is appointed, any power of the guardian or health attorney to consent to medical treatment for the person must be exercised in a way that is consistent with the health direction (unless it is not reasonable to do so).

The Commonwealth Euthanasia Act contains a provision that withholding treatment and the giving of palliative care are permitted, provided such actions do not amount to intentional killing.5

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5 *Australian Capital Territory (Self-Government) Act 1988 (Cth), s23(1B).*
Guardianship and Powers of Attorney

While they do not deal strictly with end of life decisions, other ACT law deals with substitute decision making in a health care environment. This includes the Guardianship and Management of Property Act 1991, which allows substitute decision makers to be appointed by the ACT Civil and Administrative Tribunal, as guardian, to make decisions in various domains of people’s lives including decisions about a protected person’s health care. However, a guardian appointed in the ACT cannot make end of life decisions for a protected person. In a landmark case, the ACT Supreme Court decided that a guardian had no authority to cease active treatment for a protected person (Australian Capital Territory v JT [2009] ACTSC 105).

The Powers of Attorney Act 2006 provides a framework for individuals to appoint others to make decisions on their behalf in specific areas of their lives, including in relation to their health care. An individual can direct an attorney, under an Enduring Power of Attorney, to –

- Refuse or require the withdrawal of medical treatment generally; or
- Refuse or require the withdrawal of specified forms of medical treatment eg blood transfusions; or
- Not to refuse or require the withdrawal of medical treatment generally.

The ACT Government is considering the report of the Law Reform Advisory Council into ACT guardianship law, which recommended fundamental changes to the concept of substitute decision making under ACT law.

The Australian Law Reform Commission recently completed its Inquiry into Elder Abuse. The Report made a range of recommendations regarding substitute decision making including Powers of Attorney. The Final Report recommends nationally consistent laws for enduring Powers of Attorney and a national register. The ACT Government is participating in a national working group, chaired by the Commonwealth, examining the recommendations of the ALRC report.

Human Rights Act 2004 (ACT)

The ACT Government is committed to protecting and promoting human rights, and the ACT was the first Australian jurisdiction to introduce a statutory rights instrument – the Human Rights Act 2004 (“the HRA”). In 2006 Victoria enacted the Charter of Human Rights and Responsibilities Act 2006 (Vic), legislation substantially similar to the HRA. Human rights legislation provides a framework against which law, policy and practice can be measured. Noting that most rights are not absolute and can be limited, human rights law requires that any limitations are proportionate, and can be “subject only to reasonable limits set by laws that can be demonstrably justified in a free and democratic society.”

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The Victorian Law was considered compatible with the Victorian Charter. In relation to the right to life (s 9 of the Victorian Charter, and substantially similar to s9 of the HRA), the Scrutiny of Acts and Regulations Committee (SARC) of the Victorian Parliament concluded that the legislation did not limit the right to life, because the voluntary assisted dying framework was confined through stringent safeguards to “protect against potential abuse, and by enabling people’s decisions at the end of their life to be given effect”. The SARC went on to state the Victorian Law “also recognises and promotes other important rights such as the individual rights to liberty and security, and to dignity and autonomy (which form part of the charter’s privacy right)”

Other jurisdictions with human rights legislation have considered the human rights compatibility of voluntary assisted dying schemes with human rights legislation. In the 2015 case of Carter v Canada (Attorney General), the Canadian Supreme Court struck down a prohibition on assisted suicide in the Canadian Criminal Code on the basis that it was an unjustifiable limitation on the right to life, liberty and security of person under the Canadian Charter of Rights and Fundamental Freedoms.

The HRA would provide a framework against which to assess any proposed voluntary assisted dying scheme, if legislative impediments were removed and proposals were before the Legislative Assembly.

Current practices utilised in the medical community to assist a person to exercise their preference in managing end of their life care

The ACT Government believes all Canberrans are entitled to quality palliative care, a facet of which is end of life care. Palliative care aims to relieve suffering in all stages of a life limiting disease and includes:

“symptom management; establishing and implementing care plans in keeping with the patient’s values and preferences; consistent and sustained communication between the patient and all those involved in his or her care; psychosocial, spiritual, and practical support both to patients and their family caregivers; and coordination across sites of care”

Over recent years, the ACT has focused on improving end of life care for all Canberrans through the resourcing of palliative care services and advance care planning. Palliative care is an important part of end-of-life care. The goal is to help patients achieve dignity, comfort and maximise the quality of life for patients and their carers. It also aims to fulfil choices about care style and location for those approaching death.

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8 2015 SCC 5.

9 These provisions are similar to s9 (right to life) and s18 (right to liberty and security of person) of the HRA.

According to the World Health Organization (WHO), “palliative care is 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.”

According to the WHO definition, palliative care affirms life and regards dying as a normal process, and it intends to neither hasten nor postpone death. Palliative care offers a support system to help patients live as actively as possible until death.

Palliative care and end-of-life care is increasingly becoming a field of medical expertise that considers the multiple needs of patients and plans the best multidisciplinary care options and the most appropriate setting for a patient’s ongoing treatment, with the general practitioner (GP) playing a central role, especially in the management of domiciliary care. This also involves palliative care nurses, social workers, psychologists, occupational therapists, physiotherapists, pharmacists, pain management protocols, pastoral care and sometimes hospital admission.

Providing palliative care is complex and can include a number of people who are invested in the caring process. For health professionals, the complexities include supporting and respecting the authority of the patient in the situation, while at the same time facilitating the wishes of the patient (if and where possible).

The demand for palliative care services in Australia, including the ACT, is increasing due to the ageing of the population and the increases in the prevalence of cancer and other life limiting illnesses.

The ACT is experiencing the following increases in demand for palliative care services:

- a 36 per cent increase in the number of new patients seen annually (since 2003);
- an 85 per cent increase in the number of registered clients (74 in 2002; 200 in 2014 plus 115 registered Outpatients);
- a 42 per cent increase in the average number of monthly occasions of service (since 2004); and
- a 39 per cent increase in the number of Home Based Palliative Care patients dying in hospital (since 2004).

It is noted that these large increases may be due to improved focus and reporting with the introduction of additional services.

11 [http://www.who.int/cancer/palliative/definition/en/]
For most patients at the end of life, pain and suffering can be alleviated through the provision of good quality end of life care, including palliative care that focuses on symptom relief, the prevention of suffering and improvement of quality of life. There are some instances where palliative care is not enough to achieve satisfactory relief of suffering. Certainly, even the best palliative care service cannot prevent patients sometimes asking for alternative approaches to relieve extreme suffering. Changed legislation in some states and an ongoing public discussion across Australia indicate that a consensus can be difficult to achieve due to a broad range of ethical norms and values underlying these discussions.

Palliative care services in the ACT are delivered to all people in need, regardless of diagnosis, and are provided in many settings. This includes the following areas.

**Specialist palliative care services**
The Calvary Public Hospital Bruce Palliative Care Service operates from Clare Holland House, a hospice serving the ACT and the region. This is a nineteen bed inpatient palliative care unit where a specially trained team cares for people with a life-threatening illness. It provides respite, episodic and end of life inpatient care for patients in a hospice setting. The environment is made as home-like as possible, where families can remain close and are encouraged to participate in care and decision making.

Clare Holland House is under the management of Little Company of Mary Healthcare and is fully funded by the ACT Government at a cost of approximately $6 million per annum.

The Specialist Palliative Care Consult service currently exists for inpatient and outpatient referrals to support palliative management including end of life care and serves as a link to the palliative care network of services in the ACT. The team comprises medical, nursing and allied health professionals. Referrals are taken from all specialties across Canberra Hospital and Health Services to assist in the planning and treatment of patients with life limiting illnesses. The team also provides outpatient services at the Canberra Region Cancer Centre, Canberra Hospital.

**Paediatric palliative care for hospital inpatients and outpatients**
Palliative care for children represents a special, albeit closely related field to adult palliative care. Expert paediatric input into existing palliative care services to children, young people and their families, in addition to a paediatric day stay unit at Canberra Hospital that manages maintenance chemotherapy for Paediatric Oncology patients with, at any one time, over thirty children requiring this service.

In the 2016-17 ACT Budget, more than $2m over four years was allocated for the expansion of the capacity of paediatric palliative care for both inpatients and outpatients.

**Home based palliative care through the End-of-Life Care at Home Program**
The Home Based Palliative Care supports and maintains patients living with a life limiting illness in their own home. The main objective being to enable each patient to be cared for and to die at home, if this is their choice.
Almost $2.5 million over four years was allocated in the 2015-16 ACT Budget to support the End of Life Care at Home Program to provide home-based palliative care, and education programs for health care professionals.

**Palliative care volunteer and community support services.**
The community sector is increasingly caring for people at home rather than in hospital. Palliative Care ACT receives approximately $650,000 per annum from ACT Health to ensure the delivery of palliative care volunteer support services both within Canberra Hospital and Health Services (CHHS) and in the community for people with life limiting illness, and provide a weekly professionally organised day of activities for palliative care homebound patients under professional supervision of a Registered Nurse and an Activity Officer supported by trained volunteers.

Community Options is in receipt of grant funding ($100,00 per annum for 2017-2019) to coordinate in-home (non-clinical) support services for people with end-stage illnesses and their families, and continue to improve pathways between the home-based palliative care (clinical services), hospital system and community care system (non-clinical community based palliative care).

As primary care providers, GPs often take on the responsibility to coordinate palliative care treatment having had a part of the patients care from diagnosis to end of life care. GPs often coordinate sometimes fragmented and competing community services and advocate on behalf of patients, their families and carers for community based palliative care.

**Assistance with completion of Advance Care Planning documents**
ACT Health’s Advance Care Planning (ACP) Program provides ACT residents with the ability to make informed choices about their own end of life decision. It ensures that the care and treatment ACT Health provides is respectful to the person’s own values and wishes.

The ACP Program provides a service to the residents of the ACT to assist with completion of Enduring Power of Attorney, Statement of Choices and/or Health Direction documents. These documents are then scanned to the person’s medical record so they can be assessed by ACT Health Services as required. The ACP Program also provides Calvary Hospital with copies of ACP documents.

**Research**
ACT Health also funds research projects across the ACT looking at the role and advancement of palliative care services. For example, in 2017-18, one-off funding of $262,000 was provided to the Centre for Palliative Care Research (through Australian Catholic University) to investigate integrating specialist palliative care into residential aged care.

**Nationally consistent approach**
There is also an End of Life working group established by the Australian Health Ministers Advisory Committee (AHMAC), with Professor Imogen Mitchell as the ACT Health representative. This working group has been established to make recommendations to AHMAC related to common language, common tools and strategies to raise awareness at a national level.
Palliative Care Planning
Additionally, the ACT Palliative Care Network, headed by a Clinical Leader involves clinicians working flexibly across the various service delivery settings to provide a cohesive service and address operational issues as they arise. Under the guidance of the Network, ACT Health developed a Model of Palliative Care for the ACT and Surrounding Region (Model), and Model of Palliative Care – Implementation Roadmap (Roadmap), which were completed in 2016. The Model and associated Roadmap will be used to inform the development of a new Territory-wide Model of Palliative Care Specialist Services Plan, which will effectively replace the ACT Palliative Care Services Plan 2013-17.

Work under development relating to end of life care in the ACT
The Territory-wide Health Services Framework (the Framework) is a high level strategic document that establishes the overarching principles to guide the development and redesign of health care services across the Territory over the next ten years. Under the Framework, new clinical Centres will be established to deliver better integrated care and outcomes for patients while ensuring the sustainability of ACT Health services.

Centres will be Territory-wide and will strategically group specialty services together, ensuring that they are integrated across the continuum of care and delivered in a coordinated way, by facilitating collaboration between specialties and across public, private and community based sectors with a primary focus on the individual and their family.

Centres will be supported by a Centre Service Plan and individual specialty service plans (SSPs), which will detail the service to be provided within the ACT health system. SSPs will include an outline of the service delivery model/s, patient flow, workforce requirements, interdependencies and physical resources required to deliver the service.

ACT Health will be developing a SSP for Palliative Care. Significant consultation will occur during the development of the Palliative Care SSP, including internal and external stakeholders to ACT Health. It is expected that the wider community (service providers, non-government organisations and advocacy groups) will have the opportunity to participate in the SSP development process through a consultation period currently planned for late April 2018.

In considering the SSP for Palliative Care, ACT Health will also consider broader management of end of life care, including the management of chronic pain, as well as continuing to improve inpatient care.

Legal Advice and Assistance
The ACT Public Trustee and Guardian (PTG) provides information to the community on the operations of the current decision-making framework in the ACT. PTG will provide information to members of the community about enduring Powers of Attorney where the person is seeking to appoint PTG as their attorney or alternate attorney. The Power to Choose guide available in hard copy and electronic format provides a comprehensive guide to making a Power of Attorney.
Legal Aid ACT and CHHS also recently launched a pilot legal outreach program at CHHS targeting vulnerable older people. Once a week, Legal Aid provides a solicitor in the main foyer area of TCH to field enquiries, provide advice and offer face-to-face appointments to patients on the wards. In the first five months of operation, the majority of contact has been about the role of Legal Aid and how it can assist. Legal problems raised included those regarding enduring powers of attorney and guardianship. In addition, Legal Aid has provided information to CHHS social workers in relation to elder abuse, guardianship and enduring powers of attorney.

**ACT Community views on voluntary assisted dying**

**Opinion polls**

National opinion polls over recent years indicate a high level of Australian community support for voluntary assisted dying. Most recently:

- Roy Morgan Snap SMS Survey (November 2017): of a representative cross-section of 1,386 Australians aged 18+ nationally 85% (up 11% from May 1996) of Australians are in favour of allowing a doctor to ‘give a lethal dose when a patient is hopelessly ill with no chance of recovery and asks for a lethal dose’ compared to 15% (down 3%) who say a doctor should ‘not be allowed to give a lethal dose’.  
- ReachTEL poll commissioned by Fairfax Media (October 2017): of 1,647 NSW voters found approximately 70% support changing the law to allow voluntary euthanasia for terminally ill people.
- Essential Research poll commissioned by Dying with Dignity NSW (August 2017): of 1,032 Australians aged 18+ nationally 73% of Australians indicated support for voluntary assisted dying, 15% disagreed and 12% were undecided.

In the ACT the ability to meaningfully contribute to the national debate is limited by the Commonwealth Euthanasia Act. This Select Committee inquiry provides the opportunity for the ACT community to express its views in relation to the inability of the ACT to make laws in relation to this important issue. If the Federal barriers were removed this would give the ACT the ability to have a meaningful and considered discussion about whether assisted dying should be allowed in the Territory.

This inquiry will also provide an opportunity for the ACT community to express its views about what form any such ACT laws should take, including appropriate safeguards and cultural considerations. The development of the Victorian scheme and the experience of the long-standing assisted dying laws in other countries could provide valuable learnings in considering the question of what any ACT scheme should look like, or not look like.

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The Commonwealth laws discriminate against Territory citizens by restricting the ability to introduce, through elected representatives, legislation to recognise the right to choose the manner and timing of one’s death in certain circumstances.

This is an issue not only for people who support euthanasia – it is a critical debate for all people who value the right of residents of the ACT to engage and participate in democratic processes to determine the laws that apply to them.
## Appendix A – Summary of relevant legislation and policy

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