



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

Dear Secretary

SUBMISSION TO INQUIRY ON END OF LIFE CHOICES

Thank you for the opportunity to make a submission to the Select Committee's ('the Committee') Inquiry on End of Life Choices in the ACT. This submission is written having regard to the Public Trustee and Guardian's relationship with other Australian Public Guardians in this matter and is informed by dialogue between those offices.

The Public Trustee and Guardian for the ACT (PTG) is uniquely placed to provide comment to this inquiry given the role of PTG specifically in respect to acting as guardian when appointed by the ACT Civil and Administrative Tribunal (ACAT) and attorney for health and personal matters under an Enduring Power of Attorney (EPA).

Prior to addressing the Committee's terms of reference, it is useful to provide some background.

BACKGROUND AND CURRENT ACT LEGISLATION APPLICABLE TO PTG

PTG is an independent statutory office with a broad range of responsibilities under s.13 of the *Public Trustee and Guardian Act 1985* (PTGA). PTG was formed in April 2016 upon the merger of Guardianship and Public Trustee functions into one agency. As such PTG has a similar function to interstate Public Advocates (having Guardianship responsibilities) and Public Guardians. In respect to this submission, PTG has a role to protect and promote the rights, interests and dignity of people with a decision-making disability in the ACT.

PTG provides services to some 500 persons falling into this category as a substitute decision-maker and has responsibilities to act for personal and health care matters in two distinct ways –

- as guardian appointed by ACAT under the *Guardianship and Management of Property Act 1991* (GMPA); and,

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- as attorney under an EPA pursuant to the ACT's *Powers of Attorney Act 2006* (POA) for personal and health care matters with power to refuse life-sustaining treatment.

PTG also administers five disciplines forming the Official Visitor Scheme involving visits to visitable places by some 11 Official Visitors.

PTG also has a role under s19B(1) of the PTG Act to –

- (a) represent people with a disability at hearings before ACAT in relation to guardianship applications;
- (b) investigate complaints and allegations about the actions of a guardian or manager or a person acting or purporting to act under an enduring power of attorney;
- (c) promote community discussion, and providing community education and information, about the functions of ACAT under the GMPA.

While not dealing strictly with end of life decisions, ACT law provides for substitute decision making in a health care environment.

Guardianship and Management of Property Act 1991

The GMPA, allows substitute decision makers to be appointed by ACAT 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 (*ACT v JT*), the ACT Supreme Court decided that a guardian had no authority to cease active life-preserving treatment for a protected person. In response to a request, the Public Advocate of the ACT (having responsibility for guardianship matters at the time) received advice from the ACT Government Solicitor in 2006 stating –

“in the absence of an express directive under the MTA [Medical Treatment Act 1994] it is strongly arguable that a guardian appointed under the GMP Act [Guardianship and Management of Property Act 1991] cannot make end of life decisions on behalf of an incompetent person”.

Powers of Attorney Act 2006

The POA provides a framework for individuals to appoint others to make decisions on their behalf in specific areas of their lives, including their health care. In relation to end of life choices, an individual can direct an attorney, under an EPA, to –

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

Whilst the two roles of guardian and attorney are similar there are some unique and distinct differences–

- A guardian may only be appointed by ACAT to make personal and health care decisions on behalf of a person where the person has been found by ACAT to have a decision-making disability and that they have already lost capacity to make their own decisions. An attorney, on the other hand, must be appointed for personal and health care matters by a person whilst they retain their capacity, however the attorney only has authority to act in this regard once the person has lost capacity to make their own decisions. The significant difference between the two forms of decision-making by PTG is that the attorney has an opportunity to become apprised of the person's specific wishes and needs, whereas the guardian acts in accordance

with the person's views and wishes as much as they can be ascertained including by consulting with the person's carer. Decisions are then made in accordance with decision-making principles set out in the GMPA (s. 4) or the POA.

VICTORIAN LEGISLATION

The Victorian Act (*Voluntary Assisted Dying Act 2017*) was passed in late 2017. Importantly, from the perspective of Victoria's Public Advocate (incl Guardian), the Victorian Act (which comes into effect from June 2019) only enables a person with capacity to make the decision to end their life (with additional criteria that must be satisfied, such as being close to death etc). Substitute decision makers (including guardians and people empowered under an EPA have no role in this legislation.

Victoria also has the *Medical Treatment Planning and Decisions Act 2016* (commencing February 2018) which makes some of the changes sought by the Public Advocate in Victoria, that relate to refusing medical treatment (as opposed to actively administering a drug to terminate life, which the Victorian Act covers).

TERMS OF REFERENCE

The decision-making roles PTG has in people's lives and the gravity of such decisions particularly in respect to persons with a disability are significant.

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*

The following views are consistent with those made by the Office of the Public Advocate (OPA) in Victoria in its submission to the Standing Committee on Legal and Social Issues (Legislation and References).

It is clear that the law relating to substitute consent for health care matters is complex, confusing and not well understood by medical professionals, much less the general public including private substitute decision-makers.

This is in part due to the confusing interplay of legislation including –

- *Guardianship and Management of Property Act 1991;*
- *Powers of Attorney Act 2006;*
- *Medical Treatment (Health Directions) Act 2006;*
- *Mental Health Act 2015;* and
- other informal instruments such as Advance Care Directives.

While dialogue continues to gather momentum in the community in respect to end of life decisions, medical practitioners have an important part to play and there is a need to ensure that their knowledge of existing law equips them to make appropriate decisions. Simultaneously, there is a need for clear laws to ensure that planning for the future is practical, accessible and easily applied.

Medical practitioners, in PTG's experience, whilst having authority to make decisions about a person's health and medical treatment in cases of emergency, have a preference for deferring such decisions to others to make, such as PTG as substitute decision-maker.

Another observation is that, in situations involving palliative care, medical practitioners will routinely seek formal consent to move into palliation which is a fundamental human right and does not require PTG's, or anyone's consent.

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

The ACT community is an informed and comparatively liberal society and has consistently proven to be at the forefront of legislative reform in the promotion of human rights. This has been evidenced by ACT being -

- first to enact a statutory human rights framework *Human Rights Act 2004 (ACT)*;
- first, and only, Australian jurisdiction to independently legalise same sex marriage (in September 2013, later overturned by the High Court);
- first jurisdiction to gazette Reconciliation Day as a public holiday;
- first jurisdiction to give effect to the Commonwealth's decision to implement the R18+ category in Australia;
- first to introduce altruistic surrogacy in 2004;
- highest 'yes' votes to the same sex marriage survey; and
- second jurisdiction to allow joint adoption applications by same sex-couples (2003).

ACT residents are clearly proud of the Territory, of self-government and of the ability to lead the nation on important human rights agendas. They are also proud of five times ranking the highest quality of living worldwide (Numbeo 2016) and the top ranking region worldwide in terms of well-being (OECD 2014). ACT residents enjoy an 'Open Government' which is transparent in process and information, encourages participation by citizens in the governing process, and seeks public collaboration in finding solutions (www.yoursay.act.gov.au).

PTG therefore, considers it highly likely that the ACT Community will want the opportunity for the ACT to consider legislating end of life decisions and to have their views and opinions heard on the matter.

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

The terms of reference require the Committee to consider the risks to individuals and the community associated with voluntary assisted dying and whether and how these can be managed.

The overarching principle underlying this submission is that of autonomy and personal choice. A person's fundamental right to autonomy and self-determination is particularly pertinent in relation to exercising one's end of life choices.

These rights are enshrined in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) as the most comprehensive international human rights statement on the rights of people with disability. Australian Public Guardians/Advocates note that, as a party to the Convention, Australia is obliged to implement its provisions in domestic law.

A key principle of the UNCRPD is respect for inherent dignity, individual autonomy including the freedom to make one's own choices and independence of persons. In the UNCRPD, guarantees of rights to freedom co-exist with guarantees of freedom from exploitation, violence and abuse.

Recommended reform in the ACT's Law Reform Advisory Committee's recent review of the law relating to Guardianship in the ACT in the area of substitute decision making has engaged with these competing fundamental values.

Allowing persons to make informed decisions regarding their own end of life choices may often be focused on medical interventions, when in reality the decision may be multi-faceted. As an example, a medical decision whether to resuscitate or not to resuscitate may be the focus of deliberation when completing a form on entering a nursing home, but for the person, it is often not simply a decision about medical treatment, it is about the cessation of life, the continuation of life and what that life and quality of life might that life be like.

The Victorian submission recounted the following story -

Dr Karen Hitchcock, a Melbourne physician writing in March Quarterly Essay in 2017, relates the story of Fred, a man she met in hospital who had "quite severe heart failure but still managed at home independently". Fred thought himself to be a nuisance and wanted to go to a hospice and to die. After listening to Fred, Dr Hitchcock advised him he was not a nuisance, that he should get another dog and if Fred died first she would find someone to care for the dog. Hitchcock says –

"I called him two weeks after he [Fred] arrived home to see how he was and to discuss with him his wish not to come back to hospital. He was exuberant on the phone. A dog breeder had given him a retired show dog under the proviso that should Fred ever become unable to care for her, it would be returned to them. "Can you believe that?" he said. "The one thing I was worried about, and they wanted that too!"

On Fred's wish not to come back to hospital, Fred said "Of course I want to come back if I get sick. I get silly when I'm sick. I hate everything. I say silly things." On reflection, one wonders if Fred had not had something to live for whether he would have chosen to die. If a person's life is miserable, might they be more inclined to make medical treatment decisions to bring life to an end? If life holds out some promise, some goal, might the person make different medical treatment decisions?

The quality of our lives is relevant to the decisions we make about our medical treatment.

Additional risks include the possibility of elder abuse issues, including causing the person to feel guilty about being a burden to family – this could be alleviated by stringent criteria and support processes around a person making a decision. Other risks might include potential for discriminatory practices against elderly or unwell persons, individual rights versus family wishes (e.g. a person wants to die but family are contesting this), moral and religious values and issues etc.

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

The ACT is in a unique border situation to other states/territories in that it is both a regional centre as well as a territory in its own right. Should the decision made in Victoria to allow assisted dying be emulated by NSW, this would place the ACT in a unique situation whereby residents of NSW who would then have the right to make end of life decisions, would be prevented from enacting those rights when in the ACT. This eventuality is highly likely due to the ACT having the hospitals and hospices of

choice for many persons ordinarily resident in NSW who find themselves in end of life situations in the ACT. It is submitted that this kind of legislation must be made concurrently by NSW and the ACT.

The developments in Victoria have been of particular interest to the ACT as Victoria's Human Rights Act was largely predicated on the ACT's Human Rights Act. The finding in Victoria that the voluntary assisted dying legislation is compatible with the Victorian human rights charter, opens up the possibility that any such legislation in the ACT would also be compatible with the ACT's human rights legislation.

It should be noted, as previously mentioned, that Victoria's *Voluntary Assisted Dying Act 2017* was passed in late 2017 and only enables the person themselves, when they have capacity, to make the decision to end their life. Guardians and people empowered under Enduring Powers of Attorney have no role in this legislation.

In Victoria, and also in the ACT, there are two key decision-making paradigms –

- Contractual – providing authority for decision-making in the individual and their representative. This is predicated on a person's retaining the ability to make reasonable decisions about their health care so that if/when no longer able to make reasonable judgments and there is need for a substitute decision maker, the paradigm still operates but in a modified form. This is modified in that the person is no longer acting autonomously and is subject to the decisions of another. If that decision-maker is appointed under the GMPA, that person must not only have regard to the patient's wishes but also to the wishes of the protected person's carers.

In similar manner to Victoria, the ACT applies this in a number of ways –

- The person may appoint a representative under the *Medical Treatment (Health Directions) Act 2006* (MTHDA) or an enduring attorney for health care matters under the POA Act, to make decisions for them.
- In the case of the GMPA, the substitute decision-maker most likely to be the person responsible for medical decisions will be a partner or family member who, is presumed to be familiar with the wishes, needs and aspirations of the patient. s.4 of the GMPA sets out the principles to be followed by decision-makers appointed under the GMPA, how such decisions are to be made and includes taking into account the person's wishes. s.4 also requires that a protected person's wishes be given effect to unless the decision in accordance with the person's wishes is likely to significantly adversely affect the person's interests.
- If there is no such person and ACAT appoints PTG as guardian of last resort to make decisions about medical treatment, PTG must first try to ascertain what a person's views and wishes would have been and act accordingly, otherwise PTG must act to protect the person's interests in the same way that another decision-maker would.

An advantage of this is that it is clear who has decision-making authority – the person or their representative. It is this person who can sign documents articulate decisions and responsibilities. It is this person who is accountable for the outcome of care.

- Consensual – personal autonomy under which the person or their representative accepts or refuses medical treatment which is grounded in the person's dignity and based upon the Universal Declaration of Human Rights that "all human beings are born free and equal in dignity and rights". This is enshrined in s.9 of the ACT's *Human Rights Act 2004* (HRA), "Everyone has the right to life. In particular, no-one may be arbitrarily deprived of life." and

s.10(2) of the HRA “No-one may be subjected to medical or scientific experimentation or treatment without his or her free consent.”

This process is led by clinicians but places importance on the involvement of all treating team members, patient and families in the development of the care plan. At law, ultimately it is the clinician who is responsible for the outcomes for the patient.

The NSW Health ‘Guidelines on end of life care and decision-making’ helpfully describes the rationale and approach of the consensus perspective.

“NSW Health places a high priority on health professionals working collaboratively with each other, and with patients and their families throughout all phases of end-of-life care. Such care is dependent on open and early communication in an environment of trust. These guidelines set out a process for reaching end-of-life decisions. This process promotes such communication, compassionate and appropriate treatment decisions, fairness, and seeks to safeguard both patients and health professional” and,

“A consensus building approach to end-of-life decision-making that considers the patient’s best interests as paramount is recommended where the patient lacks the capacity to determine his or her own care. This collaborative process aims to draw on the family and treating team’s knowledge and understanding of the patient’s personal values and medical condition. A consensus is sought within the treating team, and between the treating team and family about a plan of care that is as consistent with the patient’s wishes and values as possible, and which also supports the family in the degree of involvement it wishes to have.”

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

As mentioned above, PTG considers it highly likely that the ACT Community will want to have the opportunity to consider ACT legislation commensurate with the Victorian Act. As a community, ACT residents are actively engaged with championing rights, equality and having open discussion on important life issues and, as such, ACT citizens will expect to have an opportunity to contribute to the national debate around end of life decisions. Unfortunately the Commonwealth’s *Euthanasia Laws Act 1997* quells this community engagement and actively discriminates against ACT citizens by preventing the ACT joining the end-of-life discussion in a meaningful way. PTG would support the ACT Community having a chance to engage in robust discussions on this topic and that the Federal legislation unnecessarily imposes a restriction on residents of the ACT.

Yours faithfully

Andrew Taylor
Public Trustee and Guardian