



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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Submission to the SELECT COMMITTEE ON END OF LIFE CHOICES IN THE ACT

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Background:

End-of-Life Care has been a controversial medical, moral, public policy and legal issue for a number of decades. The focus has often tended to be on voluntary assisted dying, voluntary euthanasia and involuntary euthanasia; however, the issue is broader than these acute dimensions.

My own academic background is as a health care ethicist – broadly within the Catholic tradition of the ethics of health care but drawing from a distinct pool of European and British philosophy linked to relational perspectives. A key element of my doctoral work was on the ethical issues related to voluntary assisted dying and euthanasia.

Introduction:

This submission is not lengthy since I am confident that the Select Committee will be examining the rich and detailed vein of literature available on the topics. Instead, I focus my submission on two elements:

- Basis for decisions linked to end-of-life health/care/choices
- Public-policy implications related to end-of-life choices

I would be prepared to expand on these particular issues or broader matters in this sphere of discussion should the Committee want a further submission.

Basis for End-of-Life Choices:

It is clear from the literature, media reports and generalised life experiences that the kinds of decisions that people make have four levels:

- Available choices
- Views about the place of personal autonomy
- Views about the nature of society and the place of an individual within it
- Public policy perspectives

Available choices

The choices able to be made are highly relevant; currently people can seek medical and end-of-life care within particular confines – the choices are not entirely their own because medical practitioners may refuse certain treatment options or certain patient requests; additionally, as in the case of the ACT, particular specialities or treatment options are not available or not provided in a manner which permits some or many people to access them.

A significant concern, should the ACT seek to legislate for or otherwise permit voluntary assisted dying or euthanasia, these ‘choices’ may become more palatable simply due to the absence of other desirable or preferable choices. It should not be forgotten that the Northern Territory (Peron) Government only legislated for assisted dying after they could not recruit sufficient palliative care specialists. In the face of not being able to provide high quality health care, the NT Government chose to enable those who were suffering to end their lives. Some of these people would have exercised such a choice regardless of the other options but some, presumably would have opted for high quality palliative care if it had been available.

The Committee needs to consider whether including the option of assisted dying or euthanasia would enable current or future governments to simply narrow the range of other health choices available?

Evidence from The Netherlands, Belgium and Oregon would suggest that the inclusion of assisted dying measures does enable a reduction in expenditure on other health options – most worryingly including the mental health care of significant portions of the most vulnerable in communities.

The ACT already has active ‘rationing’ of health services due to a shortage of specialists, a lack of and low levels of ‘bulk-billing’ for vulnerable groups. Recent reports have highlighted issues with supply of acute mental health services, lack of adequate pain clinic options and some cancer services.

Personal Autonomy

Philosophy has always recognised a degree of tension between community perspectives and the choices of individuals. Since Descartes’ famous dictum ‘*cogito ergo sum*’, the balance has increasingly shifted toward a highly individualised approach where it is deemed that a person *can* choose any option. Behind this reasoning is a conception of freedom linked to absolute freedom – for instance, ‘I could take a gun and shoot many people in a crowd at random’. However, such a perspective does not accept any limits – physical ones like not being able to obtain a

gun, not being stopped by other people, not being constrained by my own personality or prior choices. This understanding proffers a view of people as isolated individuals unconnected from any others. It is a tempting view but it is both erroneous and inadequate.

Human persons are relational beings. Every human encounter is relational in nature and through these encounters we establish networks or webs of connections. Each connection whether purely transactional or deeply personal establishes and builds responsibilities and limits choices. Time spent with person A today limits the available time for other pursuits, at least today. Choices made about B preclude the option to choose C – at least in some instances. It is rare that popular accounts of autonomy give due appreciation to the limits of choices.

In choosing to be a member of a particular society or nation, there are other choices I eliminate from the potential options available to me. It is similar with personal choices or choices linked to health care – certain choices eliminate other choices.

A second dimension of personal autonomy is relevant here: is it the autonomy exercised in this moment or a consistent pattern of life or the expression of a future desire. The usual obvious scenario proposed is ‘would you want to live as a quadriplegic or with dementia?’ No person of good health and sound mind would answer desire such outcomes; however, it does not automatically follow that should some event occur to bring about such outcomes that it would be viewed as wholly negative. Human beings are generally poor at imagining how they will respond to adversity.

Society and Individuals

The debate over personal choice also does not pay sufficient attention to the social dimensions of being human. As a member of the human community, the Australian community, the ACT Community, I can reasonably expect access to health care and choices available to all persons in each of those communities. Beyond that, in a country like Australia any citizen should be able to expect a level care and support; to be regarded as a worthwhile contributor to the social entity. Government choices which promote exclusively individual choice may well limit social cohesion.

Rights discourse frequently elides the link between rights and responsibilities. I believe that people have a right to health care – since this view is shared by the Australian people, it is broadly recognised that the Australian community has an obligation to provide health care. It can also be contended that I have a right to end

my own life; this kind of negative right does not impose the same obligations on others. Should the Territory Government determine that assisted dying should be legalised as a 'right', who would be obliged to provide the option? This scenario is different to a person determining to end their life simply of their own volition. Part of what is sought in assisted dying is effective public support for the individual choice – effectively a mandate. Linked to this is the idea that a reputable, professional will provide the service – presumably linked to an obligation.

Members of society are certainly entitled to exercise personal choice but such choices are neither absolute, nor should they unduly bind the choices of other persons.

Public Policy Perspectives

Should the ACT Government be in a position to enable assisted dying or euthanasia there are a number of public policy implications:

What safeguards are sufficient to ensure that particularly vulnerable persons are neither coerced nor victims of their own mental state?

Will particular health professionals be mandated to provide the treatment options? Should only small numbers of professionals agree to offer the services how would this be 'advertised' and regulated? If small numbers of professionals agree to offer the services, would they be, in effect coerced into making this a larger part of their work?

How would such services be funded? Territory legislation would not automatically result in a Medicare rebate? Would health funds be obliged to provide for this treatment option? Would they, conversely still be required to offer palliative care as a part of their options?

Should the State sanction the death of citizens? Australia and its jurisdictions have determined that the State should not carry out the death penalty; we have, on the other hand, sanctioned killing by operatives of the State in both war and defence of the community/common good. Both scenarios are qualitatively different to the State agreeing that some lives are too burdensome to continue.

A high profile Australian advocate of assisted dying, Mrs Nancy Crick¹ was a person who suffered from bowel cancer was treated but had ongoing symptoms. For a variety of reasons Mrs Crick determined not to accept medical advice regarding

¹ Nancy Crick, *The Diary of Nancy Crick* [website] (2002, accessed 26 August 2003); available from [Http://pandora.nla.gov.au/pan/24513/20020424www.protection.net.au/nancycrick/htm](http://pandora.nla.gov.au/pan/24513/20020424www.protection.net.au/nancycrick/htm)

further treatment; would not accept that she was cancer free; would not accept palliative care; and, would not accept further social supports.² Following her death subsequent autopsy revealed that the medical advice provided to her was accurate: she was free of cancer and ongoing symptoms were likely to due to a 'twisted bowel'. Mrs Crick was vulnerable but her desire to end her life and refusal to accept professional advice was such that her choices were limited. She ended her life by taking a drug sent to her anonymously in the mail.

Such scenarios are also not uncommon in cases of acute mental illness: a person expressing a desire for a particular outcome that is not in their interests and not supported by professional and medical advice. At no point would a Government consider simply accepting the person's erroneous perspective and enabling their poor choice.

When Governments choose to adopt particular policy positions, there are implications. In enabling the view that some lives are just too burdensome to be endured the Government may well encourage the view broadly in the community that some lives are not worthy of existence.

I am not an advocate of 'slippery slope' arguments but I do believe that the place and power of government should be used consistently to defend life and to defend especially life that is most vulnerable.

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² See McArdle, Patrick (2008) *Relational Health Care: A Practical Theology of Personhood*, VDM Press, Saarbrücken, Germany, especially pp 61-63, 141 – 146.