



LEGISLATIVE ASSEMBLY
FOR THE AUSTRALIAN CAPITAL TERRITORY

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,
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Submission Cover Sheet

End of Life Choices in the ACT

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Michael Moore AM

Reid ACT 2612

Ms Bec Cody MLA
Chair
Select Committee on End of Life Choices
Submission on End of Life Choices in the ACT

Dear Ms Cody,

It is my pleasure to provide the following submission to the Committee.

SUBMISSION TO SELECT COMMITTEE ON END OF LIFE CHOICES

Michael Moore AM

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Declaration of potential conflicts of interest:

- I was Chair of the ACT Assembly Select Committee on Euthanasia
 - Reported in 1993 and may be found at:
https://www.parliament.act.gov.au/_data/assets/pdf_file/0011/382196/Select_com_on_enthunasia.pdf
- I was the author and Chair of the Voluntary and Natural Death Bill
- When the Federal Government introduced the Euthanasia Laws Act 1997 to over-ride ACT Legislation I asked the Assembly's Agreement to withdraw the legislation then before the Assembly

Introduction

I have been a long supporter of Voluntary Active Euthanasia (however worded – included assisted dying) as I believe where possible the autonomy of an individual should be respected to the greatest extent possible. The legislation that I originally drafted and tabled (including in a number of different forms up until 1997) carried appropriate safeguards. It is interesting to me that the safeguards in the Victorian legislation are significantly more stringent than those in the legislation that I had proposed or the legislation that was in place in the Northern Territory as drawn up by Marshall Peron.

The goal of Euthanasia is built into its very name with the word being taken from the Greek (euthanasia an easy/good death, equivalent to eu- eu- + thánat(os) death + -ia -y). Palliative care is an issue that should be considered alongside any decision on assisted dying. The best palliative care will mean that people who might otherwise have shortened their life with a “good death” or an “easy death” will be able to live longer under effective palliative care and still be able to have a good death.

The other consideration is the prerogative of the ACT Assembly (and the Northern Territory Assembly) to have equivalent powers to the States. While the States are protected by the Australian Constitution it is simply unacceptable that the Territories have a lesser status and less power on matters of moral judgement.

Note on Terms of Reference:

In response to the Committee's terms of reference I will provide an overview of the issues that I consider important and at the end of this submission will draw out the specific responses to the Terms of Reference.

Guiding Principles

A key feature of the Victorian *Ministerial Advisory Panel on Voluntary Assisted Dying*, chaired by Professor Brian Oowler, is the reliance on a series of Guiding Principles. These principles offer a framework that ought to be considered by the Select Committee. In developing a response to issues with such wide community ramifications, and attempting to balance the opposing views, these guiding principles were useful. It seems to me that to adopt such an approach based on guiding principles will also serve the *Select Committee on End of Life Choices* well. The challenge for the Committee will be to find the balance between what some consider “Nanny State” legislation, which interferes with whatever they do, versus legislation that protects community standards and does not lead to devalue life (as some will claim in a slippery slope manner).

A helpful political philosophy on this matter has been written by ANU and Princeton political philosopher Professor Philip Pettit AC and a relatively easy to read version may be found at Stanford Encyclopedia of Philosophy <https://plato.stanford.edu/entries/republicanism/> In a nutshell, Pettit argues that true freedom is more about not being dominated by others than it is about not being interfered with by others. It is the non-interference concept that underpins the philosophy of those who argue against regulation calling it “Nanny State”.

The principles outlined in the Victorian Ministers Advisory Panel's *Final Report* are as follows:

- The right to equality
- The right to life

- The right to protection from torture and cruel, inhuman or degrading treatment
- The right to privacy and reputation
- The right to freedom of thought, conscience, religion and belief
- The right to protection of the best interests of the child
- The right to liberty and security of person

I would like to draw specific attention to “the right to freedom of thought, conscience, religion and belief”. In the 1993 *ACT Assembly Select Committee on Euthanasia* a large number of the submissions were based on religious belief arguing voluntary active euthanasia somehow infringed on “God’s law”. Any such submissions ought to be dismissed on two grounds:

- The idea that in our diverse society a particular individual, or group of individuals, can be the interpreter of “God’s law” interferes with the right to such freedoms
- There is now such a high proportion of Australians who do not accept religion (with the [ABS reporting](#) “Nearly a third of Australians (30 per cent) reported in the Census that they had no religion in 2016” that religious arguments ought not to be applied.

Recommendation: *That the Committee establish and make public the principles upon which they are going to consider and evaluate submissions in this context in preparation of their report.*

Appropriate Safeguards

The concept of Voluntary Active Euthanasia was to recognise the choice people wished to make when they were in “great pain and suffering” or could foresee a time when it would be likely that they would be in great pain and suffering and would prefer to shorten their lives rather than go through what would be effectively a form of torture.

The tools to terminally end such pain and suffering are now largely in the hands of medical practitioners and out of reach of ordinary folk. As such there has been recognition of a growing need to ensure that ordinary people do have access to a good death – if that is what they choose.

In 1993 there were 214 submissions made to that Select Committee. The Committee commented that around a third of the submissions did not address the criteria but “simply expressed a view, predominantly from a religious perspective, in opposition to the intentional and non-consensual killing of patients”. There has been a significant change since that time that would have many people on both sides of the debate believing that such legislation is now possible in Australia. This view has been strengthened through the experience first in the Northern Territory and now in Victoria. No doubt there will remain a strong lobby that argues from a “slippery slope” perspective and who believe there can never be appropriate safeguards. However, appropriate legislation can mean that there is no slippery slope unless the matter is brought back to a parliament for further consideration. The goal should be to ensure appropriate safeguards in the first place.

The Victorian *Ministerial Advisory Panel on Voluntary Assisted Dying* chaired by Professor Brian Owler dealt in detail with the range of issues around appropriate safeguards.

Palliative Care and Pain Management

It is significant that the Select Committee Report on Euthanasia (1993) points out that it was “charged solely with inquiring into and reporting on the Voluntary and Natural Death Bill 1993, it nonetheless considered it important to address, in some measure, both (a) the provision of adequate palliative care and hospice facilities and (b) the provision of specialist pain management services in the Territory. In 1993 the options available were in intensive care in the Canberra Hospital or home based palliative care. I believe the debate over Voluntary Active Euthanasia played a key role in accelerating the provision of a hospice in Canberra.

This inquiry also has the potential to play a key role in ensuring even more effective palliative care in Canberra. I hasten to add that the level of palliative care delivered in Canberra is one that makes me feel proud as a Canberran. However, there is always room for improvement. I believe the improvements can take two forms:

- Further investment in palliative care in both hospice and home based care
- Stronger local training, building on the skills in both the University of Canberra and the Australian National University Medical School

Recommendation: *All efforts should be made to increase funding for greater access to palliative care and to ensure that there is a built in system of quality improvement including training through the ACT's main universities.*

Medical Practitioners' right to refuse

Professor Brian Owler, as Chair of the Victorian *Ministerial Advisory Panel on Voluntary Assisted Dying* identified in his introduction to the report that "it has been important for the Panel to provide clarity about the obligations of, and protections for, health practitioners, including the ability to conscientiously object". The report has done so effectively. Ministerial Advisory Panel Recommendation 18 states "That a health practitioner may conscientiously object to participating in the provision of information, assessment of a person's eligibility, prescription, supply or administration of the lethal dose of medication for voluntary assisted dying" The report identifies clearly that the policy intent is "To ensure a health practitioner has the opportunity to conscientiously object to participating in voluntary assisted dying".

Effective legislation will recognise that just as it is appropriate for an individual to seek assistance in dying when in great pain and suffering – it is also appropriate for a medical practitioner to seek to be excused from participation.

Power of the ACT Assembly over Euthanasia

Current power

MPs and Senators sitting in the Federal Parliament are at a much greater distance from Canberrans than their ACT Assembly colleagues. To consider their moral judgements superior to those elected MLAs who ought to be able to make such decisions is simply unacceptable. There is a high level of hypocrisy in that the Members of the Federal Parliament delegated management of the Territory – except where their judgements on morality are superior. All efforts should be made to reverse this decision and align power with the States. With this in mind, I am very pleased that the terms of reference for the Committee do address this matter.

Recommendation: *The Committee should report to the Federal Parliament the strength of feeling coming from this community engagement about the importance of the ACT having autonomy over decision making that is equivalent to the States.*

Referendum – either on ACT Assembly Powers or on Euthanasia

I would humbly suggest the reintroduction of a referendum as an appropriate concept for gauging the ACT community views on the powers of the Assembly.

In 1997 following the Federal Parliament's adoption of the Kevin Andrews legislation I attempted to argue that the government should run a referendum in order to gauge community opinion. The intention was to strengthen the ACT argument with the Federal Parliament. At the time of the introduction of the *Euthanasia Referendum Bill 1997* on 18 June 1997, I presented the idea of running a referendum concurrently with the 1998 election. The schedule to the Bill provided the approach:

In these questions "voluntary active euthanasia" means the termination of the life of a mentally competent adult person at his or her request if he or she has a terminal illness and is enduring pain and suffering that he or she considers intolerable.

- 1. Do you believe that voluntary active euthanasia should be permitted by law?*
- 2. Do you support the following statement?*

The people of the ACT call on the Commonwealth Parliament to restore to the ACT Legislative Assembly the power to make laws with respect to voluntary active euthanasia.

The opportunity exists to test the community opinion and could be addressed in this manner.

Recommendation: *Consult formally with the community through a referendum asking about either euthanasia or powers of the Assembly or both.*

The Terms of Reference

This submission has touched on the Terms of Reference both in the broad concepts and in the particular. These reflections may be helpful for the Committee.

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 ACT Community is well-served by committed palliative care professionals. As outlined in this submission above – there is always room for improvement in access and availability. I also believe that appropriate investment in training of all people working in palliative care will enhance the end of life experience for people who die in the ACT.

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

Polls have constantly shown strong support across Australia, and even stronger support in the ACT, for voluntary assisted dying. However, there is an opportunity to gauge this effectively and to influence the Federal Government by running a referendum on this issue. It would also demonstrate the ACT Assembly's commitment to effectively engaging formally with the people of Canberra.

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

Non-action in this area has greater risks than taking action to regulate. The risks associated with voluntary assisted dying can be mitigated effectively with appropriate protections in place and limitations on scope of practice. This has been demonstrated clearly in the Victorian Ministers Advisory Panel Report and in the Victorian legislation. The greater risk is continuing without regulation in this manner where people take action into their own hands and resort to violent means to end their own pain and suffering.

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

I have discussed the issue of the Victorian legislation throughout this submission. This legislation has taken a very conservative approach and may well limit the application too narrowly. There are certain deteriorating conditions that may also be associated with or parallel to dementia. Consideration needs to be given to a "living will" that sets the circumstances on which a final decision can be made.

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

I have addressed this issue above. In order to assess the level of community support and strengthen an argument for the Federal Parliament, I believe a referendum on voluntary assisted dying and on the power of the Federal Parliament to over-ride ACT Community values on moral or ethical issues ought to be strenuously challenged.

Any other relevant matter.

There is a key issue on autonomy and freedom that underpins this legislation. Understanding freedom in terms of non-domination rather than non-interference is important in establishing the principles on which such legislation should be based. As indicated above, in the Victorian Ministerial Advisory Panel Final Report, such principles provide an effective framework for consideration of the issue of voluntary assisted dying.

Conclusion & Recommendations

I would like to take the opportunity to present the recommendations from this submission to the Committee:

1. **Recommendation:** *That the Committee establish and make public the principles upon which they are going to consider and evaluate submissions in this context in preparation of their report.*
2. **Recommendation:** *All efforts should be made to increase funding for greater access to palliative care and to ensure that there is a built in system of quality improvement including training through the ACT's main universities.*
3. **Recommendation:** *The Committee should report to the Federal Parliament the strength of feeling coming from this community engagement about the importance of the ACT having autonomy over decision making that is equivalent to the States.*
4. **Recommendation:** *Consult formally with the community through a referendum asking about either euthanasia or powers of the Assembly or both.*

Thank you for the opportunity to make a submission to the Committee. I would be delighted to have the opportunity to elaborate on any the issues above should it be useful to the Committee.



Adjunct Professor Michael Moore AM

4 April 2018