Monica Doumit
[redacted]

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The Chair
Legal and Social Issues Committee
Parliament of Victoria
By email: lsic@parliament.vic.gov.au

Dear Mr O'Donohue:

Submission for Inquiry into End of Life Choices

I am writing to express my thoughts on this very important inquiry.

While I am not a resident of Victoria, I would like to comment because I am a trained lawyer with 10 years legal experience. I also hold a Bachelor of Medical Science from the University of Technology, Sydney and a Masters of Bioethics from the University of Sydney. Moreover, I believe that the decisions made in Victoria will affect the rest of the country.

Terms of reference and the question of voluntary euthanasia and/or assisted suicide

I have had the opportunity to review a large number of the submissions already provided for this inquiry. I notice that although the terms of reference for the inquiry do not mention the issue of voluntary euthanasia or assisted suicide, the submissions all consider this to be the issue at hand.

I think this highlights the real challenge for the Committee in ensuring that good end-of-life care is provided in Victoria – most people associate "end-of-life" care with assisted dying, and ignore the other aspects of care. This ignorance left unchecked risks attention being taken away from end-of-life care, particularly palliative care.

To that end, I would like to focus the bulk of my submission on palliative care.

Report of the Auditor-General

In April 2015, the Victorian Auditor-General released an audit into palliative care in Victoria, and in particular, "whether Victorians with a terminal illness have access to high-quality palliative care that is timely, coordinated and responsive to their needs and wishes."

The Auditor-General's findings and conclusions included:

- Some metropolitan community palliative care services are struggling to cope with increasing demand, with audited health services concerned that their patients are not always able to access palliative care at home in a timely way.
- More needs to be done to promote and embed advanced care plans across the health system.
- Further work is needed to ensure carers and families can access support at critical times, particularly, provision of respite and access to psychosocial support.
- Families and carers shoulder enormous responsibilities and psychological stress, as well as the financial pressures associated with withdrawing from work.
- The current monitoring framework of the Department of Health and Human Services (**DHHS**) is overly complex, and some reporting mechanisms are not adequately developed to measure progress, meaning the DHHS is limited in its ability to provide assurances about the palliative care sector.
- Coordination of palliative care is hindered by lack of access to integrated patient management systems.

While no doubt those involved in the provision and audit of palliative care do great work, the audit shows there is still much to be done in this area, both to provide adequate services and to give the community confidence that they will be able

AIHW report on Palliative care in Australia

A 2014 report from the Australian Institute of Health and Welfare gave a picture of the provision of palliative care services in Australia. This report noted that there were an estimated 148 specialist palliative medicine specialists working in Australia, with approximately 31,500 patients.

What I think these figures might tell us is that the demand for palliative care in Australia is high, and not matched with the number of specialists we have.

Research from the GroundSwell Project

According to its website, the Groundswell Project is a not for profit organisation known for using innovative arts and health programs to create social and cultural change about death and dying. They report:

- 75% of Australians have not had end of life discussions;
- Over 70% die in hospital though would prefer to die at home; and
- Less than 10% die with an Advance Care plan.

These figures are incredibly important, because one of the factors in the persistent push for euthanasia is fear of death. Euthanasia and assisted suicide advocates often speak about these practices as a form of "control." It makes sense that we seek to control something we fear. But euthanasia provides a false sense of "control." And what people are really looking for is not so much control, but a sense of peace around dying. Increased education about, and discussion of, end-of-life choices can assist this greatly.

Concluding thoughts

The above reports tell us that there is a demand for palliative care not just in Victoria, but across Australia, and there are some limitations in the provisions of these services, a lack of cohesion amongst them, and a strain on carers. Additionally, there is fear surrounding death because we do not speak about it or plan for it enough.

The Committee would do well in proposing that these issues be addressed through additional resources and education programs, rather than considering euthanasia as a panacea to these very complex issues around service provision.

Yours faithfully

Monica Doumit B Med Sc. LLB (Hons). M. Bioeth.