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Committee Secretary
Senate Standing Committee on Legal and Constitutional Affairs
Department of the Senate
PO Box 6100
Parliament House
Canberra ACT 2600
Australia

Dear Sir or Madam,

Re: Inquiry into the Rights of the Terminally Ill (Euthanasia Laws Repeal) Bill 2008

I make this submission in my own name only and not in the name of my institute, of any Government Committees in which I am involved or of any organisation.

This period during which submissions have been requested has been a difficult personal time as I am dealing with my own terminal illness (combination of renal failure, advanced ischaemic heart disease and Rheumatoid auto-immune disease) and some adjustments to the palliative care regime that allows me to keep functioning. I apologise for submitting late and express the hope that my submission will still be received.

I have had a long-term involvement in this issue as a hospital ethicist and consultant in bioethics. Recently also I had the experience of chairing the National Health and Medical Research Council Working Committee preparing guidelines for the care of people in an unresponsive state or a minimally responsive state and receiving a large number of public submissions on that topic which is closely related to the topic of your enquiry. The strength of submissions from people who care daily for Australia's most dependant and needy individuals was overwhelming and I highly recommend that you read the public submissions on the NHMRC's web-site.

I would like to record my own view that it would not benefit the people who live in the Australian Territories, particularly those who are terminally ill, if the *Euthanasia Laws Act 1997* were repealed. The current legislation serves to give some measure of protection against the terminally ill being regarded as a burden. By preventing the addition of legalised euthanasia it makes it more likely that adequate efforts will be made by those governments to make better provision for palliative care services. Legalised euthanasia would give those governments a political "out" in that respect.

Every year I receive from my health insurer a letter that tells me how much it costs the fund to maintain my health care. I dread receiving that letter and the psychological reasoning that would seem to motivate it. Each year I am reminded how much of a burden I am to my

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community. The fear of being a burden is a major risk to the survival of those who are chronically ill. If euthanasia were lawful, that sense of burden would be greatly increased for there would be even greater moral pressure to relinquish one's hold on a burdensome life.

Medical research in this area indicates that the desire for euthanasia is not confined to physical or psychosocial concerns relating to advanced disease, but incorporates hidden existential yearnings for connectedness, care and respect, understood within the context of the patients' lived experience. Euthanasia requests cannot be taken at face value but require in-depth exploration of their covert meaning, in order to ensure that the patients' needs are being addressed adequately.¹


If euthanasia is a legitimate option with a determined structure, such as was the case in the Northern Territory for a brief period, then life for the chronically seriously ill would become contingent upon maintaining a desire to continue in the face of being classified as a burden to others.

I ask simply that the committee find in favour of the status quo in this request.

It should also be pointed that of the seven deaths that happened under the terms of the Rights of the Terminally Act in the Northern Territory permitted euthanasia, four did not actually meet the criteria². The legislation was manifestly unsafe and I would argue that legislation that permits euthanasia could never be made safe for those of us who have serious chronic illnesses, because the essence of such legislation is to make respect for our lives contingent upon the strength of our will to survive.

That desire to live is often tenuous in the face of suffering and in the face of the burden our illnesses impose on others, our families and the wider community. You would gain nothing worthwhile for us by supporting the legalisation of deliberately ending the life of those who request death. Such requests warrant a response in solidarity from our community, a response that seeks to give us more support and better care, rather than termination of both life and care.

Yours sincerely,



Assoc Prof Nicholas Tonti-Filippini PhD

¹ Yvonne Yi Wood Mak and Glyn Elwyn "Voices of the terminally ill: uncovering the meaning of desire for euthanasia" *Palliative Medicine*, Vol. 19, No. 4, 343-350 (2005)

² David W Kissane, Annette Street, Philip Nitschke, 'Seven deaths in Darwin: case studies under the Rights of the Terminally Ill Act, Northern Territory, Australia,' *The Lancet*, 1998 Vol 352: 1097-1102