

Assoc Prof Nicholas Tonti-Filippini
BA (Hons) MA (Monash) PhD (Melb)

Saturday, 20 November 2010

The Hon Mike Rann MP
Premier of South Australia
Parliament of Australia
State Administration Centre
200 Victoria Square
Adelaide SA 5000

Dear Mr Premier,

Re: Voluntary Euthanasia Bill 2010

I write this letter to you 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. I write because what happens in South Australia on this matter will affect all Australians, particularly those who, like me, meet the requirements of the Bill.

Relevant to this matter is the fact that I am dealing with my own terminal illness (combination of renal failure, advanced ischaemic heart disease and Rheumatoid auto-immune disease) and am dependant on haemodialysis and palliative care. I have undergone 15 angioplasty procedures and the placement of eight stents to attempt to recover some blood flow after the failure of coronary bypass surgery. The last such procedure was unsuccessful as the blocked artery could not be accessed. The Rheumatoid disease causes chronic pleuropericarditis. I mention these matters only to establish that I am no stranger to suffering and disability, and am well aware of the limitations of palliative care. It is particularly difficult to control chronic pain because the effectiveness of most forms of pain relief is of limited duration, given the development of therapeutic tolerance. I have reached the limits of what palliative care can offer.

I cannot speak for all people who suffer from illness and disability, but think I can speak more credibly about suffering, illness and disability than those people who advocate for euthanasia presenting an ideological view of suffering and disability. Facing illness and disability takes courage and we do not need those euthanasia advocates to tell us that we are so lacking dignity and have such a poor quality of life that our lives are not worth living.

Professionally, I have been involved with issues to do with the care of the terminally ill for many years, having been Australia's first hospital ethicist, twenty-eight years ago, at St Vincent's Hospital, Melbourne, where I was also Director of Bioethics for a period of eight years. Since then I have been a consultant ethicist in private practice and have taught ethics in

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the medical faculties of the University of Melbourne and Monash University, before taking my current position at the John Paul II Institute. The Institute is associated with the Lateran University in Rome and is a registered Higher Education Provider in Australia offering accredited specialist graduate courses in Bioethics and in Theological Studies in Marriage and Family.

Also relevant is that recently I had the experience of chairing a National Health and Medical Research Council (NHMRC) 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. The topic 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 or at least read the NHMRC *Ethical Guidelines for the Care of People in an Unresponsive State or a Minimally Responsive State (2008)*. Importantly, the guidelines provide a careful analysis of the way in which care decisions may be made so as to preserve respect for the dignity and worth of people who are so profoundly disabled and to provide care for the families and others who care for people with PCU or MRS.

I have also had a long-term association with a home hospice service that serves the eastern area of Melbourne. I would like to record my own view that it would not benefit seriously ill South Australians, particularly those who are terminally ill and suffering intractably, if the *Voluntary Euthanasia Bill* became law. The current legal situation in South Australia, while not perfect, does provide a measure of protection against the terminally ill being regarded as a burden. As a chronically ill person I know well what it is to feel that one is a burden to others, to both family and community, how isolating illness and disability can be, and how difficult it is to maintain hope in the circumstances of illness, disability and severe pain, especially chronic pain.

For several years, until I objected, I received from my health insurer a letter that tells me how much it costs the fund to maintain my health care. I dreaded receiving that letter and the psychological reasoning that would seem to have motivated it. Each year I was reminded how much of a burden I am to my 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. Seriously ill people do not need euthanasia. We need better provision of palliative care services aimed at managing symptoms and maximising function, especially as we approach death. Rather than help to die, the cause of dignity would be more greatly helped if more was done to help people live more fully with the dying process.

The proposal to make provision for a terminally person who is suffering to request, and a doctor to provide, assistance to die makes it less likely that adequate efforts will be made to make better provision for palliative care services. Legalised euthanasia would give those responsible for funding and providing palliative care a political "out" in that respect.

In Australia, too little is done to make adequate palliative care available to those who need it:

- Current entry requirements for palliative care usually exclude people with chronic pain and is often limited to people who are in the last stage of cancer with a prognosis of less than eight weeks;
- The pharmaceutical subsidies for the more effective forms of pain relief are often restricted to cancer patients;
- People living outside major cities have little access to palliative care facilities.
- Few doctors are adequately trained to provide palliative care.
- Such palliative care services as exist are chronically underfunded and struggle to provide the complex range of services that are needed to assist a person to live with pain and disability.
- Most pain clinics are over subscribed and have long waiting lists. For people who are left suffering, such waiting is unconscionable.

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 patient's 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 In Australia, what is needed is often not available or not available in time. It is distressing to note that in the US State of Oregon in 2009, none of the patients who were lawfully killed at their own request were referred for formal psychiatric or psychological evaluation. It is also distressing to note that two thirds of people lawfully killed under euthanasia laws, in those jurisdictions that permit it, are women.

If euthanasia is a legitimate option with a determined structure, such as was the case in the Northern Territory for a brief period, and is now proposed for South Australia, 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. Essentially the Bill involves setting up a category for people whose lives may be deliberately ended. Their protected status as a member of the South Australian and Australian communities depends on a contingency. Passage of the Bill would imply that our community considers that our continued survival depends on us not succumbing to the effects of pain and suffering, depends on us not losing hope.

I ask simply that the committee find in favour of the status quo in this respect. We need protection and encouragement from our community, we do not need this form of discrimination. Far from protecting the dignity of those who are seriously ill and suffering, the Bill would undermine dignity by undermining our sense of individual worth as a person, no matter our suffering and disability.

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)

It should also be noted that of the seven deaths that happened under the terms of the Rights of the Terminally Act in the Northern Territory that 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. Such legislation depends on each of us, who have a serious illness and are suffering, not losing hope. If euthanasia is lawful then the question about whether our lives are overly burdensome will be in not only our minds, but the minds of those health professionals and those family members on whose support and encouragement we depend. The mere existence of the option will affect attitudes to our care, and hence our own willingness to continue.

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.

I note that the Bill has some safeguards including:

- REQUIREMENTS for two doctors, including a specialist, to examine the person making the request.
- DEMANDING a psychiatrist be consulted if either doctor believes the person is not of sound mind or acting under "undue influence".
- CREATING a Voluntary Euthanasia Board with powers to intervene if any relevant medical practitioner believes a request for euthanasia should not be granted.
- There will be strict obligations on witnesses, jail terms of up to 20 years for misleading statements, and a ban on for-profit centres and the promotion of voluntary euthanasia by insurance companies

However there are many problems with the *Bill*, in summary:

- The *Bill* has a very wide scope, it affects not just those who are imminently dying. The definition of "terminal illness" includes people who may be months or years away from their illness causing death. As a person whose life depends on extraordinary care, including haemodialysis for four x four hour sessions each week, on that basis alone, I fit the description. I also have severe angina throughout those sessions, caused by the haemodynamics of the treatment and my own compromised coronary flows, and I have

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

many other episodes of pain throughout the day, including waking at night in pain. Whether that is a profound level of pain and/or distress depends on the support that I receive from those close to me, as much as it depends on my own will. That euthanasia is not offered to me is important to that response. People who are ill and disabled need that support and encouragement and the knowledge that those around them value them.

- The Bill has not been generated by a broad-based enquiry that took into account the interests of all South Australians, and especially those with chronic or terminal illness. It is a narrow approach that excludes the provision of adequate care and support for those in need, and appears to be more a matter of ideology than a genuine attempt to respond to the range of matters that affect us.
- The Bill would expect the doctors involved to prescribe a drug not for legitimate purposes that define the medical vocation, such as the care of the patient or the treatment of illness, but to intentionally and actively intervene to end the life of the patient. In that respect, the Bill is not supported by the Australian Medical Association or any of the medical Colleges. The AMA's policy on euthanasia is to "strongly oppose any bill to legalize physician-assisted suicide or euthanasia, as these practices are fundamentally inconsistent with the physician's role as healer"³.
- The Bill has not been supported by organizations and institutions directly involved in aged care, the care of the dying or the care of those with chronic illness. Those involved in the day to day care are generally not in favour of being given the capacity to end the lives of those they care for.
- The Bill would not benefit South Australians who suffer from chronic illnesses. Instead it would make protection of their lives dependant on the strength of their will to continue. 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 and to remove that burden from the lives of others.
- The Bill is based on a notion of unbearable pain. A major part of pain experience and our capacity to tolerate it is what is sometimes called "existential pain". Pain of an existential nature arises usually from loneliness and a lack of sense of self worth. The option of euthanasia provides an out for families and carers, and the fact that the option exists would be likely to make someone who had a burdensome illness feel even less valued and increase the likelihood that they would choose death over dying alone or being a burden to others. Serious illness and dying are times when a person needs the support of others so that others can share empathy with that person⁴. The possibility of opting instead for a fatal

³ http://www.ama-assn.org/apps/pf_new/pf_online accessed 15/5/08

⁴ 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)

prescription would cast a shadow over those relationships and would be likely to undermine the person's wish to be wanted and valued.

- Pain and suffering are complex involving physical, psychological, emotional and spiritual elements. Palliative care seeks to address the needs of those who are suffering in a multi-disciplinary way that reflects the many elements involved⁵. Crucial to good palliative care is the support of the patients socially, emotionally and spiritually. It is not simply a matter of relieving physical pain. For those who continue to live with a burdensome illness, the option of euthanasia would undermine one of the essential elements of good pain relief, the notion that the person is supported, loved and wanted.
- In other places, such as the United Kingdom, for instance, which have adopted very liberal policies on other social policies, such as reproductive technology, gay unions and abortion, the Parliaments have strongly opposed euthanasia because euthanasia cannot be made safe for people who are seriously ill and thus vulnerable. It is worth noting that jurisdictions such as the Netherlands and Belgium that legalised euthanasia, lacked the availability of the kind of palliative care services that developed in the UK.
- Euthanasia law cannot be made safe. The Northern Territory briefly had similar law. As discussed above, several of those for whom the legislation was implemented did not in fact meet the criteria of the Act despite the safeguards.⁶ This is reflected also in the Dutch experience where much larger numbers than were expected have been subject to the law, raising human rights concerns, see United Nations' concern below.
- Euthanasia is contrary to the International Human rights instruments. When the Human Rights Committee of the United Nations considered a euthanasia law enacted in the Netherlands to codify what had become euthanasia practice, the Committee said that where a State party seeks to relax legal protection with respect to an act deliberately intended to put an end to human life, the Committee believes that the International Covenant on Civil and Political Rights obliges it to apply the most rigorous scrutiny to determine whether the State party's obligations to ensure the right to life are being complied with (articles 2 and 6 of the Covenant). The Committee expressed the concerns that the new Act (in the Netherland) contains a number of conditions under which the physician is not punishable when he or she terminates the life of a person, *inter alia* at the "voluntary and well-considered request" of the patient in a situation of "unbearable suffering" offering "no prospect of improvement" and "no other reasonable solution". The Committee also expressed concern lest such a system may fail to detect and prevent situations where undue pressure could lead to these criteria being circumvented. The Committee was also concerned that, with the passage

⁵ Hudson Peter, Kristjanson Linda J, Ashby Michael , Kelly Brian, Schofield Penelope, Hudson Rosalie, Aranda Sanchia,, O'Connor Margaret, Street Annette.(2006) A systematic review of the desire for hastened death in patients with advanced disease and the evidence base of clinical guidelines *Palliative Medicine* 20, 693-71

⁶ 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 Note that one of the authors, Nitschke, was a major proponent of the Northern Territory legislation.

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of time, such a practice may lead to routinization and insensitivity to the strict application of the requirements in a way not anticipated. The Committee learnt with unease that under the present legal system more than 2,000 cases of euthanasia and assisted suicide (or a combination of both) were reported to the Netherlands' review committee in the year 2000 and that the review committee came to a negative assessment only in three cases. The large numbers involved raise doubts whether the present system is only being used in extreme cases in which all the substantive conditions are scrupulously maintained.⁷

I would welcome the opportunity to discuss this letter and the matters raised by the *Voluntary Euthanasia Bill 2010* further.

Yours sincerely,

Assoc Prof Nicholas Tonti-Filippini PhD

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<http://www.unhchr.ch/tbs/doc.nsf/0/dbab71d01e02db11c1256a950041d732?OpenDocument&Highlight=0,euthanasia> Accessed 26/5/08

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FATHER Peter TONTI

SENIOR BROTHER HEARNS

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