

**Submission to the Senate Legal and Constitutional Affairs Committee
regarding the Rights of the Terminally Ill (Euthanasia Laws Repeal) Bill 2008.**

The legacy of the 6 month period in which the Northern Territory's Rights of the Terminally Ill Act 1995 was operating still has repercussions that continue to play out in the Northern Territory today. I wish to address these issues in stating my case against any legislative repeal of the Commonwealth's Euthanasia Laws Act 1997 that would lead to the re-enactment of the Northern Territory's Euthanasia legislation.

1. Ongoing public fear that referral and engagement of palliative care services will lead to a patient being euthanased placing considerable stress on patients at a vulnerable time & reluctance to engage with services

Although popularist opinion states that the majority of Australians are in favour of euthanasia, the reality I believe, when a patient is actually in their dying phase can be very different. It is one thing to say you are in favour of euthanasia when death is at a distance from you but I would maintain that the majority of people dying still want to engage in the life that is left even though death may be inevitable and fast approaching.

As a consequence, I am constantly reminded, since coming to the Northern Territory as a palliative care specialist, that unlike my previous positions interstate, a fear remains that admission to palliative care services, particularly admission to the Darwin Hospice is still considered a pathway to being euthanased. For the majority of patients reassurance and promises have to be given that we do not participate in the practice of euthanasia before patients will accept services or hospice admission. Delays such as these can cause unnecessary symptom escalation. These fears continue to play out as appropriate symptom management with medication changes can be stalled through fear that any changes in medication, especially pain medication escalation, is a move towards the intentional intervening in the ending of life. Patients, carers, families and palliative care staff often talk about the burden the patient feels in these circumstances and could euthanasia be an option; the reality is that rarely does the patient express disappointment that we aren't able to offer euthanasia, although family and carers may remain vocal in their distress.

More broadly the concept of intervening in the "finishing off" processes of indigenous Australians is an anathema to their cultural practices. Making up 31% of the Northern Territory's population, indigenous Territorians, still express a great deal of fear from any medical intervention around the time of death, particularly the giving of symptom relieving medication. Even though a great deal of palliative care education and training for indigenous community members and indigenous health services staff has been undertaken over the years, the perception, from the previously enacted euthanasia legislation, that any medical intervention is seen as being euthanasia and was the cause of death remains. This not only lead to the immediate issues of psychological and physical payback and social ostracism for family members and clinic staff, but as many public health workers have highlighted, plays out in being a significant factor in the non-engagement of indigenous people in any general health prevention and treatment programs. The fears are also seen with the active withdrawal or non-engagement with services at time of dying in case doctors or nurses euthanase.

2. Inadequate guidelines within the NT Rights of the Terminally Ill Act 1995 does not define what an adequate engagement of palliative care services may be and forces undue burden & scrutiny on these services, particularly the pressure for the NT palliative care medical practitioners to become complicit, as a signatory, to the process.

Within the Act the provision of palliative care services and a medical practitioner whose work is in the palliative care of a patient's condition is required to consult and provide a necessary signature. It is very difficult with the act in its current form to see these guidelines as anything but a potential "rubber stamp", a reality that has been expressed by the palliative care medical and nursing personnel who were present in 1996/97.

What constitutes appropriate and adequate palliative care? Palliative care in providing the physical, emotional and social support is about taking time to establishing relationships, developing trust and connections to manage the many elements that come into play as people approach their end of life. Palliative care services across the Territory have undergone continuing development since 1996, such that we have now meet and are above recommend Australian targets for staffing and service provision as well as consulting with up to 25% more patients per 100,000 than is recommended to be attained. 1.

However, an interstate visitor who travels to the Territory to utilise legalised euthanasia could in the past, and could in the future arrive meet with their local doctor, have their CT scan to demonstrate disease progression and have their appointment with a palliative care specialist on the same day and said to have experienced adequate palliative care, hence having completed significant steps on the path to being euthanased. One consultation with a palliative care worker would not be considered by the field as appropriate or adequate palliative care. Who then defines and signs? Do the palliative care physicians have to acquiesce to the pressure brought to bear and become complicit in this process he or she is unlikely to agree with? Do they resign and leave as the physician eventually did in 1996/97? Does the Territory have to struggle to attract palliative care doctors to work under such circumstances in an already under supplied workforce?

Staff working in palliative care acknowledges and support each other in the emotional stress that such work brings. Staff who worked in the Territory at the time of the previous legislation comment on the undue burden and scrutiny, the "chaos" in which they had to try and do their normal work as well as meet the demands from fearful Territorian patients who feared being covertly euthanased, the euthanasia "tourists" who moved from interstate and clogged working time sifting through their cases, the imposed accountability to Territory and Commonwealth health department demands, the overt media scrutiny as well as the persistent and covert plethora of media posing as family members to gain stories and access to patients. Do we really want to return to this situation?

3. The majority of pressure that is brought to bear to intervene and assist a patient's end-of-life is brought to bear by family members rather than the patient themselves. Do the guidelines really protect patients from these pressures?

With the developments of advanced care planning as normal health practice and its increasing uptake from jurisdictional to operational level of health service provision, patients are more confidently making it known what they consider are their treatment needs and options. Although patients readily express fears and anxieties about end – of-life issues, often in the Territory reflecting their sense of being a burden to family and friends, I believe again the reality is at odds with popular opinion that expression of distress and burden and speaking of euthanasia does not mean that people wish to then act upon it. As discussed before I believe, the majority of people dying still want to engage in the life that is left even though death may be inevitable and fast approaching. At this stage families members are caught up in their own distress at being present at a love ones end-of-life. Requests to intentionally intervene to cease peoples lives predominantly comes from the distressed family members. Rather than allowing the dying person to have the death they want, vested interests want the death to ameliorate the family member/friend's suffering. With advanced directives and the enacting of a medical agent to act on a patient's behalf when they no longer have capacity, how can we be certain that the agent is acting with the patient's intentions in mind or are we going to be acquiescing to the pressure and wishes of the family and its medical agent to intentionally intervene?

In conclusion, the window in which the Northern Territory's Rights of the Terminally Ill Act 1995 was operating has given us, I believe, a demonstration as to why we should not consider re-enactment of this or similar legislation to allow euthanasia. No one wishes undue suffering on anyone. People's perception of their own potential to suffer and their distress at bearing witness to death and dying of a loved one is naturally going to tip polls to indicate that euthanasia should be available to all. However, in the day-to-day practice of being present to people's dying I see the stress and the unnecessary fears and anxieties that remain for patients and the ongoing implications for patient's non-engagement within the health system if euthanasia was again a reality.

1. Palliative Care. Service provision in Australia: a planning guide. Palliative Care Australia, Canberra 2003

Dr Mark Boughey

Palliative Care Physician

MBBS, BMed Sc, FRChPM, Dip Pall Med, MPH

Darwin, NT