



AUSTRALIAN  
FEDERATION OF  
AIDS  
ORGANISATIONS  
INC.

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Peter Hallahan  
Committee Secretary  
Senate Standing Committee on Legal and Constitutional Affairs  
Department of the Senate  
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Dear Mr Hallahan

I am writing to make brief submission in relation to the ***Rights of the Terminally Ill (Euthanasia Laws Repeal) Bill 2008***.

The Australian Federation of AIDS Organisations (AFAO) represents Australian HIV/AIDS community based organisations at a national level. Our membership includes state and territory AIDS Councils, the National Association of People Living with HIV/AIDS (NAPWA), Scarlet Alliance (the national organisation representing sex workers), and the Australian Injecting and Illicit Drug Users League (AIVL). AFAO develops and formulates policy on HIV/AIDS issues, advocates for our member organisations, and promotes medical and social research into HIV/AIDS and its effects. NAPWA is also signatory to this submission.

I would like to commend the Australian Government for considering this action to effectively repeal the *Euthanasia Laws Act 1997*, thereby allowing the Northern Territory, the Australian Capital Territory and Norfolk Island to legislate for the rights of people who are terminally ill. The previous Government's enactment of the *Euthanasia Laws Act* was anti-democratic in that a body from outside the Northern Territory overrode a law enacted by the democratically elected members of the Northern Territory Government who had carried out extensive debate and inquiry.

As the *Rights of the Terminally Ill (Euthanasia Laws Repeal) Bill* will likely proceed to a conscience vote (should it proceed at all), I feel it would be disingenuous to make this submission without reference to the issue of euthanasia and the content of the Northern Territory's *Rights of the Terminally Ill Act 1995*.

The profile of HIV has changed significantly since our submissions on this issue in the mid 1990s. Fortunately, successful interventions to limit HIV transmission and the wide availability of effective anti-retroviral therapies has seen a decline in the annual number of AIDS-related deaths in Australia from a peak of 735 people in 1994 to 94 people in 2006. While HIV is now a chronic manageable disease for many, some will die each year from complications associated with AIDS and will experience acute and extreme pain, suffering and distress.

Whether or not people with HIV represent a special interest group in relation to a desire to access euthanasia is, unfortunately, under-researched. That being said, it can be strongly argued that the right to live with dignity has been a central tenant of the way people with HIV/AIDS have positioned themselves as they have fought for the right to seek health information and treatment, engage with health professionals and be self determining in the way they live their lives. The logical corollary of this approach to life is that in cases where an individual believes their pain and loss of dignity is too great to bear, they seek some control over the time and means of their death.

The reality is that people are exercising control over their own lives. In many instances this has taken the form of drafting 'living wills', 'advanced directives on treatment' and enduring powers of attorney. In other instances, some seek assistance to end their own lives at a time they choose despite the fact that doing so is illegal. Numerous studies and polls suggest that acts of euthanasia and assisted euthanasia are not isolated occurrences. Roger Magnusson's (University of Sydney) work on HIV positive people also reveals cases of 'botched' suicide attempts resulting from euthanasia's illegality, and the dreadful impact on all involved.

The Northern Territory's *Natural Death Act 1988* allows doctors to withdraw treatment in some circumstances despite their knowledge that doing so will result in death. Many doctors have also made it a matter of public record that they have taken actions that resulted in a person's life being shortened or terminated when that person has been in the latter stages of a terminal illness. These actions have been performed under the banner of palliative care, although it is known that the (genuine) pain relief provided is highly likely to expedite that person's death. Laws allowing patients to refuse medical interventions mean those requiring interventions or life support are 'lucky' – they can refuse. Others whose conditions are as painful or worse, are given only the right to refuse palliative care to reduce their pain, ironically the same care which may eventually expedite their deaths.

The Northern Territory Government's drafting of the *Rights of the Terminally Ill Act 1995* reflected a genuine desire to develop a legal framework to more humanely address the needs of those who are terminally ill, in great pain and despair, while reflecting general community attitudes towards voluntary active euthanasia. Although there is significant opposition to voluntary euthanasia in some quarters, Australian surveys and polls generally reflect that the majority of Australians do not object to those who are terminally ill and in distress being given the right to choose the conditions of their deaths.

Opposition to the Northern Territory's legislation has included numerous ill-conceived objections. One being that it was the first such legislation in the world; an argument unconvincing per se, as all legislation has been introduced somewhere without precedent, and frequently with some advantage to society of the day.<sup>1</sup> Another was that it represented a 'slippery slope' towards unregulated suicides and assisted suicides, claims which have included inappropriate use of ambiguous data and obnoxious references to historical state based killings.

In fact, the Northern Territory legislation includes clear protections and safeguards for the legislation's application. It limits application to a person 18 years or older who, as a result of their terminal illness, is experiencing pain, suffering and/or distress to an unacceptable extent. The patient must have been informed of the nature of their illness

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<sup>1</sup>Also noting that voluntary euthanasia does operate in a limited number of other jurisdictions under different legislative models.

and all available options for medical treatment and care. Information about palliative care must be given by a medical practitioner with specialist palliative care qualifications. A psychiatrist must ensure the patient is not suffering from a treatable clinical depression in respect to their illness. The doctor must be satisfied that the patient is of sound mind, has made the decision freely and after due consideration, including consideration of all implications to the patient's family. It precludes those with any financial interest from being involved, makes it illegal to promise 'reward or advantage' to a doctor who assists, or to threaten or cause disadvantage to a doctor who refuses to assist.

The Senate Legal and Constitutional Legislation Committee's *Consideration of Legislation Referred to the Committee Euthanasia Laws Bill 1996* contained the following advice:

In the course of the inquiry, and in the course of the debate in the community, much has been made of anecdotal evidence of individuals dying in harsh circumstances. Such extraordinary circumstances warrant the most compassionate response for the person themselves and for the carers and family involved. Regardless of whether or not euthanasia might be the appropriate response in such circumstances, the task before the Committee, and in turn before the Senate, is to determine how a change in the law so as to allow such a response, stands up as a matter of public policy. No question as serious as euthanasia should be settled on individual cases.

AFAO would argue the case to the contrary. It is our submission that when individual cases are clinically evaluated and confirmed for their presentation and specific circumstances, and it is evident there are no other options to relieve a person's pain and distress, that it is entirely appropriate to have a process whereby that person can rationally request an end to their life. It is also consistent that the legislative framework should be able to offer a humane and sanctioned process for supporting that individual's decision in as safe and dignified way as humanely possible.

Surely when no other options are open to a person in the final stages of a terminal illness, a person suffering unrelievable pain and distress who consistently and rationally requests an end to their agony, there should be some process whereby their dying wish can be granted.

Yours faithfully

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Executive Director

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Executive Director  
National Association of People Living With HIV/AIDS (NAPWA)