Submission concerning the Rights of the Terminally Ill (Euthanasia Laws Repeal) Bill 2008

I attach a submission in support of Senator Brown's Bill

The Northern Territory Legislation was the result of a democratic process, which gave people a right that the majority of them wanted, and which nobody who did not want it was forced to exercise.

The Northern Territorians were not alone in wanting this right. It seems as though the majority of citizens in 'protestant' countries want this right too. And, of course, some of them now have it. Switzerland has had it for a very long time with no evidence of ill effects.

As I understand it, opposition to the Northern Territories legislation was based (at least in part) on the following factors and arguments:

1. Voluntary euthanasia offended the religious beliefs of some parliamentarians and doctors.

2. There was no need for voluntary euthanasia because palliative care was/is so good.

3. There were dangers that the legislation would have us all sliding down slippery slopes to:

    a. (massive) overuse of the provision of voluntary euthanasia

    b. compulsory euthanasia.

In the following submission I try to address several features of these points and arguments, and to review some of the evidence. In the time available, I have not been able to review more than a sample of the relevant factual evidence, but I have not knowingly omitted any research which disagrees with my point of view.

I have given references to the cited research in footnotes.

Thank you for the opportunity to present this submission.

Emeritus Professor Philip Ley

A. DO PEOPLE WANT VOLUNTARY EUTHANASIA AND/OR PHYSICIAN ASSISTED SUICIDE?

1. Are people in general in favour of voluntary euthanasia?

Public opinion in most 'western' countries is overwhelmingly pro voluntary euthanasia – usually more than 70 percent are in favour..

2. Are doctors in favour of doctor assisted suicide and voluntary euthanasia.

When medical professionals are asked about it, findings are more mixed. For example in a recent survey in Victoria 53 percent of doctors were in favour of legalised voluntary euthanasia, and in a recent major review of several surveys of US doctors the average percent in favour of legislation to allow doctor assisted suicide was 54 percent (range 31% to 71%). The average percent in favour of legislation allowing active euthanasia by doctors was 51 percent (range 35% to 71%).[1]

The same review found that the mean percents who would participate if assisted suicide were to be legalised was 36% (range 18% to 57%), and an average of 26% would participate in active voluntary euthanasia (range 8% to 57%).

Furthermore, an average of 12% admitted to having participated in assisted suicide (range 2% to 53%), and 4% admitted to having participated in active voluntary euthanasia (range 2% to 5%)

To the extent that one can generalise from these figures it looks as though there would be a sufficiently large number of doctors to make doctor assisted suicide and voluntary euthanasia a viable proposition if the law were to be changed.

It will also be recalled that an Australian survey found that, in practice, many Australian doctors take steps that lead to an earlier death for patients. I quote the summary of this well-known piece of Australian research [2].

> "The proportion of all Australian deaths that involved a medical end-of-life decision were: euthanasia, 1.8% (including physician-assisted suicide, 0.1%); ending of patient's life without patient's concurrent explicit request, 3.5%; withholding or withdrawing of potentially life-prolonging treatment, 28.6%; alleviation of pain with opioids in doses large enough that there was a probable life-shortening effect, 30.9%. In 30% of all Australian deaths, a medical end-of-life decision was made with the explicit intention of ending the patient's life, of which 4% were in response to a direct request from the patient. Overall, Australia had a higher rate of intentional ending of life without the patient's request than the Netherlands."

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[1] Dickinson, G. E., Clark D,, Winslow, M, & Marples, R. (2005) US Physicians' attitudes concerning euthanasia and physician-assisted death. *Mortality*, **10**, 43 – 52.

[2] Kuhse, H., Singer, P., Baume, P., Clark, M. and Rickard, M. (1997) End-of-life decisions in Australian medical practice. *Medical Journal of Australia*. **166**, 191 - 197

B. REASONS FOR WANTING THE OPTION OF VOLUNTARY EUTHANASIA.

Reasons include the following (figures in brackets give the percent of the Oregon euthanasees who cited this as their reason, or as one of their reasons [3]):

To avoid helplessness and loss of control of their lives (96%)

To avoid indignity (76%)

To avoid loss of independence and not being able to participate in activities that made life enjoyable (96%)

To avoid pain and suffering to oneself (48%)

To avoid pain and suffering to loved ones.

Other research has looked at the sort of death that people say they would like – the factors which for them would constitute a good death. It would appear that their top priorities include the following (the percentages shown are taken from a recent Dutch survey) [4]: (Note the similarities to the reasons given by those who chose assisted suicide in Oregon)

A good death would involve:

- Being able to say 'goodbye' to loved ones (94%)
- Being able to die with dignity (92%)
- Being able to decide for themselves the treatments they do and do not want to receive (88%)
- Freedom from pain ((87%)

These expectations are of course not always met, and, all too often, the experience of dying people is far distant from these ideals. For example, a survey of the last days of dying people reported that [5]:

> "Almost 40% of conscious patients had severe pain (range, 34% for patients with chronic obstructive pulmonary disease to 46% for patients with colon cancer). With the exception of patients with colon cancer (and elderly persons, whose surrogates were not asked about pain), more than half of patients with serious illness had severe dyspnea in the last 3 days of life. Severe confusion was found in

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[3] http://oregon.gov/DHS/ph/pas/index.shtml.
[4] Rietjens, J. et al. (2006) Preferences of the Dutch general public for a good death. Palliative Medicine, 20, 685 - 692
[5] Lynn J, Teno JM, Phillips RS, Wu AW, Desbiens N, Harrold J, Claessens MT, Wenger N, Kreling B, Connors AF (1997) Perceptions by family members of the dying experience of older and seriously ill patients. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. *Ann Intern Med.* **126**, 97-106.

> almost one fourth of all cases. In all condition categories, fewer than one in eight patients had severe nausea. Fatigue was the most prevalent symptom, affecting almost 80% of patients in each of the categories. Surrogates reported that almost three fourths of patients (73%) found it difficult to tolerate these physical symptoms."

Further,

> "In the last 3 days of life, 55% of patients were conscious. Among these patients, pain, dyspnoea, and fatigue were prevalent. Four in 10 patients had severe pain most of the time. Severe fatigue affected almost 8 in 10 patients. More than 1 in 4 patients had moderate dysphoria. Sixty-three percent of patients had difficulty tolerating physical or emotional symptoms. Overall, 11% of patients had a final resuscitation attempt. A ventilator was used in one fourth of patients, and a feeding tube was used in four tenths of patients. Most patients (59%) were reported to prefer a treatment plan that focused on comfort, but care was reported to be contrary to the preferred approach in 10% of cases. Conclusions: Most elderly and seriously ill patients died in acute care hospitals. Pain and other symptoms were commonplace and troubling to patients. Family members believed that patients preferred comfort, but life-sustaining treatments were often used."

C. OBJECTIONS TO VOLUNTARY EUTHANASIA

1. Objections arising from religious beliefs

Many people who oppose voluntary euthanasia do so on religious grounds.

But the issue is <u>voluntary</u> euthanasia. Those with religious beliefs forbidding euthanasia do not have to avail themselves of it. Nor does anybody, religious or not, have to take up the option.

And, of course, religious beliefs might not be true – they certainly cannot all be true, as different religions and sects have different beliefs. If, as some/many believe, the idea of God is a delusion, then laws should not be based on any arguments that rely <u>solely</u> on the assumptions of God's existence, or the Divine Will.

Believers should of course be allowed to order their own conduct according to these factors (provided that non-believers and people of different religious persuasions are not seriously disadvantaged thereby) but they should not be allowed to force non-believers to accept their (possibly wrong) creeds.

In fact, in a secular democracy it is probably a wise principle to insist that government legislation should still be defensible <u>even if</u> the religious beliefs of its supporters or opponents are one day shown to be false.

There should always be a logical/empirical (non-religious) case for any legislation.

2. Palliative care

It is sometimes argued that there is no need for voluntary euthanasia because palliative care makes voluntary euthanasia unnecessary.

But, is palliative care as good as some people think?

The short answer must be 'No' – or, at least, 'probably no'. Recall the findings reported earlier [6]:

> "Almost 40% of conscious patients had severe pain more than half of patients with serious illness had severe dyspnea in the last 3 days of life. Severe confusion was found in almost one fourth of all cases. In all condition categories, fewer than one in eight patients had severe nausea. Fatigue was the most prevalent symptom, affecting almost 80% of patients in each of the categories. Surrogates reported that almost three fourths of patients (73%) found it difficult to tolerate these physical symptoms."

Further,

> "In the last 3 days of life, 55% of patients were conscious. Four in 10 patients had severe pain most of the time. Severe fatigue affected almost 8 in 10 patients. More than 1 in 4 patients had moderate dysphoria. Sixty-three percent of patients had difficulty tolerating physical or emotional symptoms. Overall, 11% of patients had a final resuscitation attempt. A ventilator was used in one fourth of patients, and a feeding tube was used in four tenths of patients. Most patients (59%) were reported to prefer a treatment plan that focused on comfort, but care was reported to be contrary to the preferred approach in 10% of cases.

This is not to denigrate the many devoted workers who provide palliative care, nor to deny that they have frequent successes in at least ameliorating terminal symptoms – especially pain. It is just to point out that palliative care is far from universally successful in providing painless and easeful ends of life.

It is impossible to here review all of the evidence, but there can be no doubt that palliative care is in need of much improvement before it can be confidently offered as

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[6] Lynn J, Teno JM, Phillips RS, Wu AW, Desbiens N, Harrold J, Claessens MT, Wenger N, Kreling B, Connors AF (1997) Perceptions by family members of the dying experience of older and seriously ill patients. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. *Ann Intern Med.* **126**, 97-106

a substitute for voluntary euthanasia. To illustrate this fact we need go no further than to consider the vast amount of research being currently conducted to try to improve it.

For example, the recent *Annals of Internal Medicine* review of attempts to improve palliative care cites 152 references to recent research studies.[7] (Many of these were themselves meta-analyses of several sets of research findings)

Another example is the US Government's Department of Health and Human Services 2004 report, 'End of Life Care and Outcomes'[8] which runs to 651 pages.

With demonstrably (proven) effective remedies (e.g., antibiotics) there is never such a voluminous literature.

In addition, it should also be noted that palliative care cannot necessarily address several of the problems (mentioned earlier), which lead to people wanting voluntary euthanasia.

3. The slippery slope: How many people make use of voluntary euthanasia.

In reading what follows it is worth considering the possibility that knowing that suffering and problems can be painlessly terminated when one wishes, probably makes it easier for many people to persevere. In this respect it is interesting that in the Oregon statistics, it looks as though several people did not use their drugs immediately[9]. I quote:

> "During 2006, 65 prescriptions for lethal medications … were written. Of these, 35 patients took the medication, 19 died of the underlying disease, and 11 were alive at the end of the year. In addition 11 patients with earlier prescriptions died from medications."

This obviously suggests that at least some people wait for a while before taking the medication.

So, what percentage of dying people actually avail themselves of voluntary euthanasia where it is an option for them?

The percentage of all deaths due to voluntary euthanasia and doctor-assisted suicide has been reported as[10]:

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[7] Lorenz, K. A. *et al*., (2008) Evidence for improving palliative care at the end of life. *Annals of internal Medicine*, **148**, 147 - 159

[8] US Department of Health and Human Services (2004) Evidence Report/Technology Assessment No 110. *End of life care and outcomes.* The report can be downloaded in full at: http://www.ahrq.gov/downloads/pub/evidence/pdf/eolcare/eolcare.pdf

[9] Full details of the statistics are available at : http://Oregon.gov/DHS/ph/pas/index.shtml.

[10] Hurst, S. A & Mauron, A. (2003) Assisted suicide and euthanasia in Switzerland. *British medical Journal*, **326**,, 271-273

The Netherlands	0.3% of deaths
Oregon	0.09% of deaths
Switzerland[11]	0.45% of deaths

Obviously in countries where voluntary euthanasia/assisted suicide is an available option, it accounts for a quite small percentage of deaths.

(For comparison, the percentage of deaths due to suicide (of all sorts and for whatever reason) in Australia, has varied in recent years from 1.3 percent to 2.1 percent - ABS 2006 figures)

D. A CASE IN POINT

Finally, most people would, I think, understand why Chantal wished to die, and I suspect that only the most doctrinaire would wish to see her request denied. You will remember that this poor woman not only had a very painful and distressing progressive inoperable cancer, it had also grossly disfigured her. The pain, the breathing difficulties and the disfigurement were increasing rapidly, and it looked as though her eye might pop out in the near future. She seems to have had friends and support, but still preferred to die.

Which of us would wish to claim the right to deny her request?

QuickTime™ and a
TIFF (LZW) decompressor
are needed to see this picture.

[11] Swiss law, of course, differs from the others. There, anybody can assist in voluntary euthanasia (assisted suicide) provided that their (the helper's) motive is altruistic – thus easing the burden on the medical profession.