Dear Committee members,

On behalf of members of Pro-Life Victoria, please accept the following submission.

High quality palliative care is being provided in Victoria but is far from universal. It provides enormous benefits to many people in their final days and months. Victorians deserve a concerted effort to extend the provision of high quality palliative care as much as possible.

Just as good palliative care practitioners see a request for euthanasia first as a cry for help, we need our members of Parliament to inform themselves sufficiently on calls for euthanasia to see that we must improve the provision of high quality palliative care. This is not to suggest that pain and suffering can always be averted but there is room to generate a substantial improvement in end of life care. It is the appropriate response to substantial evidence that this committee will receive indicating that for some Victorians, poor outcomes have been experienced in terms of the quality of end of life care.

The existing power of Medical Attorney plays an important role for many in end of life decision making. Greater promotion of this has potential to improve end of life choices. This also needs attention.

The use of advance care directives is bringing risks that situations faced by patients are being addressed with reliance on documents signed when specific circumstances and treatment options and prognosis were unknown and not envisaged. When the option of signing such a directive is presented to a person, there may be a number of alternative standard wordings that a patient could readily find themselves agreeing to sign depending largely on the type of information given to them at the time by medical staff.

The alternative wordings are likely to have outcomes in a wide range of potential future situations as different as white and black - life and death. The alternative wordings presented will determine whether medical treatment is pursued or excluded. Although a specific situation may not be addressed in a care directive, medical staff will have to interpret the applicability of the document’s wording and even if it does not cover the
circumstances, it would seem inevitable that the signed document will be used beyond the circumstances envisaged and skewing the decision making. We are concerned that the quality of information that will be provided to patients around directives will generally be deficient. The alternative standard wordings provided are also likely to be inadequate for many situations that may later emerge.

Even in the best circumstances in terms of information and alternative wordings, there remains a deep concern that specific circumstances will very often differ from what was envisaged in terms of prognosis and treatment options. The medical profession will be obliged to interpret the intention of an advance care directive signed without knowledge of specific circumstances. The attitudes of patients in difficult situations may in any case be quite different to the views that might have been provided at a time when the current situation was not imminent.

It is for these reasons that advance care directives will create greater problems if they are allowed to have impact beyond the treatment of existing conditions.

The risks of poor outcomes due to inadequate communication between medical practitioners, patients and their families appear to be increasing in the context of financial pressures in health care. These interrelated issues of inadequate communication and financial pressures make it even more inappropriate for euthanasia to be permitted in any circumstances. The same issues also increase the risk of advanced care directives being applied in situations in which were not envisaged when they were signed.

**Proposals for Legislative Change For Euthanasia**

Federalism is such that the issue of euthanasia has been tested carefully many times by various State governments. Governments all around Australia have carefully considered and ultimately rejected the prospect of legalising euthanasia. After some very extensive and thorough inquiries, legislators have recognised that the laudable practice of withholding overly burdensome treatment can be maintained without resorting to the homicidal intent which characterises euthanasia.

The 1995 Northern Territory legislation was thoroughly discredited by the assessment of the Federal Parliament and also by a review of its operation that appeared in the *Medical Journal of Australia* in 1998 (Kissane DW, Street A, Nitschke P. Seven deaths in Darwin: case studies under the rights of the Terminally Ill Act Northern Territory, Australia. *Lancet* 1998; 352: p1097-1102).

As detailed in the abovementioned review, the Northern Territory legislation proved to be poorly drafted and open to abuse during its period of operation in 1995-96. Its intended safeguards against abuse and protection of the innocent and vulnerable very quickly proved inadequate.

The Northern Territory legislation was correctly viewed as requiring that the Federal Parliament protect Australians from its consequences.

The legalisation of euthanasia is frequently promoted emotionally on the basis of the most difficult cases but particularly on this issue, hard cases would make bad law. The legalisation of euthanasia would increasingly encourage the elderly to see themselves as a
burden. Euthanasia would destroy both life and dignity in more ways than is commonly appreciated.

The best palliative care physicians see a request for euthanasia as invariably being a cry for help. Terminally ill patients commonly face higher risk of depression and this is more often the case if their medical treatment and pain relief is in need of improvement.

Inquiries into these issues have presented many positive recommendations such as the promotion of palliative care. The emphasis of palliative care techniques is to control pain and distressing emotional symptoms when medical treatment of a curative nature is no longer of any avail and the terminal stage has been reached.

It would be helpful if the current inquiry could also add its support for initiatives to improve the care of the terminally ill and to emphasise that a request for euthanasia should always be an indicator that requires a further effort to ensure that the best medical possible care is being provided.

Pro-Life Victoria shares the concerns presented in a submission prepared by The Linacre Centre for Healthcare Ethics for the House of Lords Select committee on the Assisted Dying for the Terminally Ill Bill (Sept 2004). We believe the submission contains vital information that is particularly relevant to this Inquiry.

Therefore the resume and conclusions reached by The Linacre Centre for Healthcare Ethics are presented here in Attachment 1.

An evaluation of outcomes of legalising euthanasia in the Netherlands formed a major part of the Linacre Centre submission. It is also extracted from the submission and included here as Attachment 2.

Pro-Life Victoria requests that the Committee peruse the information in these two attachments.

Yours faithfully

Denise Cameron
President
Pro-Life Victoria

Peter Beriman
Vice President
Pro-Life Victoria
Resume and Conclusions (Extracts) of Submission to the House of Lords Select Committee on the Assisted Dying for the Terminally Ill Bill

on behalf of

The Linacre Centre for Healthcare Ethics

September 2004

Resume

Euthanasia is standardly defended by reference to one or both of two considerations: autonomy and welfare. Either consideration can lead to much more widespread euthanasia than defenders of its legalisation had originally envisaged.

If euthanasia is about patient choice, why should the patient need to be terminally - or physically - ill to receive it?

If euthanasia is about benefiting the patient, why should patients who cannot request it be deprived of this benefit?

Thus we see in the Netherlands an extension of euthanasia to those who are mentally ill or ‘tired of life’, and also to significant numbers of patients who have not consented to it – including patients who could have consented but in fact have not.

In this submission, we argue that respect for the patient’s life is part of respect for the patient’s human dignity, and that palliative care, not euthanasia, is the morally appropriate response to terminal suffering. The law should continue to uphold human dignity and equality by prohibiting homicide/assisted suicide for disabled and able-bodied alike. Suicidal people should not be confirmed in their own estimate of their lives’ value; instead, they should be supported and protected, whatever their physical condition.
Conclusion

To conclude: a doctor’s willingness to kill some patients – whether because this is their ‘choice’ and/or because the doctor thinks their lives have no value - undermines a commitment to the patient’s true welfare which is basic to medicine.

Voluntary euthanasia is not a ‘private’ choice: it very much affects (among other things) the character of doctors, and their treatment of other patients. Once legalized, euthanasia would become a ‘quick fix’ for disposing of ‘difficult’ patients in response to the demands they make on care.

Medicine would be robbed of the incentive to find genuinely compassionate solutions to the difficulties presented by such patients. The kind of humane impulses which have sustained the development of hospice medicine and care would be undermined, because too many would think euthanasia a cheaper and less personally demanding solution.¹

Doctors would be mistrusted by patients, who would die in an atmosphere of suspicion. Many patients would be killed without request, even if this remained illegal.

The suicidal would be confirmed in their estimate of their lives’ value, while the non-suicidal would be, at least, disheartened by the public view of lives such as theirs. For all these reasons, it is vitally important that society continue to value the lives of all its members, including those who, in pain or distress, do not see their own lives as worthwhile. Euthanasia betrays the suicidal by accepting their own view of their lives: suicidal people, whatever their physical condition, need protection and support.
(Extracts) of Submission to the House of Lords Select Committee on the Assisted Dying for the Terminally Ill Bill

on behalf of

The Linacre Centre for Healthcare Ethics

The Netherlands

The position of euthanasia advocates who stress both ‘autonomy’ and ‘welfare’ considerations is inherently unstable. There is not just a ‘logical’ but a ‘practical’ instability: either consideration can lead in practice to much more widespread euthanasia than was originally envisaged in official guidelines. Thus in the Netherlands we see both an extension of euthanasia to those who are mentally ill or ‘tired of life’ and its extension to those who are unable to consent, such as infants and young children. Indeed, there is now official toleration of non-voluntary euthanasia, in that (for example) euthanasia of children is required to be reported. In 2001, 100 out of 1088 deaths of babies under one year of age involved the giving of drugs with the explicit purpose of ending life.

Three major Government-ordered studies of euthanasia and other end-of-life decisions have been carried out in the Netherlands, where euthanasia was accommodated for many years by court decisions before being legalized by statute. These studies show a far from reassuring picture with regard to observance of guidelines, including the requirement that

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2 With regard to grounds for euthanasia, 3% of doctors say that they have themselves assisted suicides of people ‘tired of life’ who did not have any serious somatic or psychiatric ailment (G. van der Wal, A. van der Heide, B.D. Onwuteaka-Philipsen & P.J. van der Maas, Medische Besluitvorming aan het einde van het leven: De prektijk en de toetsing procedure [Medical Decisionmaking at the End of Life: The Practice and the Review and Verification Procedure] (Utrecht, 2003), p.104, Table 10.2). 29% of doctors consider this an acceptable motive for assisted suicide (Ibid, p.107).

3 In Belgium, too, where euthanasia has recently been legalized, a member of the Belgian House of Representatives, Madame Avontroot, claims that many cases of non-voluntary euthanasia are performed, without even the family’s consent, and that the number of cases registered after a year (203) is far below the real number (see the electronic briefing of the Institut Européen de Bioéthique Quality of Life – Spécial Belgique January-June 2004, p.8). The president of a commission evaluating the law on euthanasia, Dr Distelmans, recently called for the law to be extended to minors and those with degenerative conditions such as Alzheimers who had made an advance request (Ibid, p.2).

4 Van der Wal, van der Heide et al., p.121.
the patient give consent. In the studies, the term ‘euthanasia’ is used in the official Dutch sense of ‘active voluntary euthanasia’; moreover, not all deliberate life-terminating acts - let alone deliberate life-terminating omissions – are classed as ‘euthanasia’, ‘assisted suicide’ or ‘life terminating acts without request’. To arrive at a more realistic, though still conservative, figure for euthanasia in the Netherlands, it is necessary to count all acts – and if possible, omissions – on the part of doctors which are chosen with the ‘explicit intention’ (or ‘explicit purpose’) of ending life. These figures are available for 1990 and 1995; however, the data for 2001 make it impossible to determine the exact level of (for example) non-voluntary active killing, since doctors who gave intentional overdoses of painkillers with the intention of hastening death were not asked, as in previous years, if the patient had consented.

4.1 Compliance with guidelines

When we read that 900 patients were deliberately killed without their request in 1995 (a figure which rose to 980 in 2001) we should remember that this figure, alarming as it is, does not include 1,537 cases where palliative drugs were given with the explicit, unrequested aim of hastening death. If we include this group of cases, it becomes clear that more than a third of those actively killed were killed non-voluntarily. Even excluding this group of cases of active non-voluntary euthanasia, one in five of those actively killed were killed without their request. If we turn to euthanasia by omission, there were as

5 For an in-depth analysis of the first two studies, together with much other useful material, see J. Keown, Euthanasia, Ethics and Public Policy (Cambridge, 2002). For a summary statement of striking results of these studies which come into view when the terminological ambiguities are clarified, see J. Finnis, ‘Euthanasia, Morality, and the Law’, Loyola University of Los Angeles Law Review 1998, Vol.31, pp.1123-45 at pp.1125-8.

6 As John Keown comments on the 1995 study, ‘A note to the relevant questions [on withholding/withdrawing treatment with the explicit intention/purpose of hastening death] states that an intention to “hasten the end of life” could also be understood as an intention “not to prolong life”. This creates an unfortunate ambiguity … An intention not to prolong life is not the same as an intention to end it. In many of these cases doctors may have intended to withhold/withdraw treatment not to end the patient’s life, but because the treatment was futile or too burdensome’ (op cit., pp. 129-130).


8 Keown, op.cit., p.128. The larger figure includes assisted suicide.
many as 18,000 such cases in 1995,\(^9\) of which 14,200 – a substantial majority - were without the patient’s request. It is worth noting that by no means all the patients killed without request, whether by act or by omission, were incompetent at the time.\(^{10}\)

### 4.1.1 Reporting

It is often said that euthanasia will be better controlled where it can be freely reported.\(^{11}\) In fact the Dutch experience shows widespread underreporting, in addition to widespread disregard of other guidelines. About half the cases of ‘euthanasia’ and ‘assisted suicide’ revealed by the 2001 survey went unreported, as did 99% of cases of termination of life without the patient’s request, 100% of cases of intentional lethal overdose of painkillers (whether requested or unrequested), and a huge majority of cases where the patient killed was a child.\(^{12}\)

This is in line with earlier research, which found that between 15% and 20% of doctors said they would not report their euthanasia cases under any circumstances, and that 20% of doctors’ most recent unreported cases involved ending life without consent.\(^{13}\) Such cases, both the 1990 and 1995 studies revealed, were virtually never reported.\(^{14}\) Even

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\(^9\) See note 8.

\(^{11}\) A comparative study of six European countries (A.van der Heide *et al.*, ‘End-of-life decision-making in six European countries: descriptive study’, *Lancet* June 17, 2003, published online at [http://image.thelancet.com/extras/03art3298web.pdf](http://image.thelancet.com/extras/03art3298web.pdf) ) shows a high rate of euthanasia in the Netherlands, and a relatively high, if not the highest, rate of non-voluntary life termination. (It is worth stressing that not all cases of active non-voluntary killing – much less non-voluntary killing by omission – will be included in these figures.)

\(^{12}\) R. Fenigsen, ‘Dutch Euthanasia: The New Government Ordered Study’, *Issues in Law and Medicine* 2004, Vol. 20, No. 1, p.77. It is striking to note that in 3% of these cases, the baby was euthanised without the consent or knowledge of the parents (Van der Wal, van der Heide *et al.*, Table 12.2) and that similarly in three cases older children were euthanised without the request of either the child or the parents (Table 13.2).


where euthanasia takes place ‘with consent’, there is a real possibility of pressure being brought to bear by doctors and/or relatives. It is startling to note that more than 50% of doctors surveyed thought it appropriate to suggest euthanasia to patients.\textsuperscript{15}

As one researcher comments, ‘When, as the 1990 and 1995 studies document, 59% of Dutch physicians do not report their cases of assisted suicide and euthanasia, when more than 50% feel free to suggest euthanasia to their patients, and when 25% admit to ending patients’ lives without the patient’s consent, it is clear that terminally ill patients are not adequately protected.’\textsuperscript{16} Most striking of all, in both the 1995 study\textsuperscript{17} and the 2001 study,\textsuperscript{18} the authors suggest that it is the patient who is responsible for avoiding termination of his life: if he does not wish euthanasia, he should say so clearly, orally and in writing, well in advance.


\textsuperscript{16} Hendin, \textit{op.cit.}, p.234.


\textsuperscript{18} Van der Wal, van der Heide \textit{et al.}, p.201.