

Submission for the Inquiry into End of Life Choices

Legal and Social Issues Committee of the Victorian Legislative Council

Dr. Patricia Newell

I am a medical specialist working in the Melbourne metropolitan area. I have over 20 years of experience in anaesthesia, caring for chronically, and terminally ill patients on a regular basis. I also treat patients with acute pain, and liaise with chronic pain specialists in this capacity. Members of my own family have suffered from advanced cancer. I am therefore very familiar with the role and limitations of medical care at the end of life, and empathise with the families of the terminally ill.

I welcome this opportunity to express my concerns about the availability of medical care to Australians during chronic illness, and at the end of life.

I will also explain why I believe physician assisted suicide and active euthanasia is harmful to patients and their carers, and should not become an accepted part of medical practice.

Australians only have choices in end of life care when adequate palliative care services are available to them. This is not currently the case for everyone.

Not enough is done in Australia to make palliative care available to those with terminal illnesses. The Australian and New Zealand Society of Palliative Medicine states that a minimum ratio of 1.0 full time equivalent (FTE) palliative medicine specialists per 100,000 population is required to provide an adequate service. The Institute of Public Welfare 2013 Report on palliative care services in Australia found that the average ratio was only 0.4 nationally, and 0.3 in Victoria. People who live in rural areas have even poorer access to palliative care services, as the ratio is even lower outside the major cities. [1]

The inadequacy of current services, and inequity in access to palliative care, is a serious issue.

There can be no meaningful discussion about end of life care choices until there is better medical care available for the chronically and terminally ill.

I would like to emphasise that euthanasia and physician assisted suicide are not a substitute for palliative care.

Specialist clinics for patients who live with long-term pain are also under funded. Some of my patients are left suffering for months before they can see a chronic pain specialist. Improved funding for chronic pain services is urgently required.

There is a need for more frequent discussion with patients and families about their wishes for end of life care, that is, advanced care planning. During my career I have at times witnessed well-meaning but overly aggressive treatments for critically ill patients. Doctors are trained to intervene to save lives, and families may not feel empowered to refuse treatment on behalf of a relative. Knowledge of the expressed wishes of a patient may assist doctors and families with making decisions when the ill person is unable to do so. I would caution, however, against making Advanced Care Directives which are legally enforceable.

I regularly encounter situations where medical care plans, such as obstetric care plan (birth plans) or blood product preferences, however well researched, tend to fail when an unforeseen complication arises. In addition, patients may change their minds as their situation changes. I think that discussions should be documented as Advanced Care Plans. People that have been diagnosed with a terminal illness, as part of their management, should be encouraged to nominate a person who understands their wishes, and can therefore make appropriate decisions on their behalf, when the need arises (that is, a medical power of attorney.)

There is much public confusion about the definition of euthanasia, which hinders constructive discussion about this issue. Good medical care does not attempt to prolong life at any cost. I concur with Palliative Care Australia position that “declining or withdrawing aspects of treatment is acceptable if it aligns with the informed wishes of the patient.” [2].

It is widely accepted that withholding futile or burdensome medical treatment, is not unethical. The withdrawal of machine-assisted life support may be appropriate in some circumstances. The provision of adequate pain relief, at the end of life, may hasten death as a secondary outcome (the double effect principle). None of these actions constitute euthanasia or physician assisted suicide. Active euthanasia, that is, ending the life of a patient by a deliberate act, is in conflict with basic ethical principles of medical practice. [3]

Some individuals feel strongly that they should be able to legally request active euthanasia or assisted suicide. Much of this stems from a fear of pain and distress at the end of life, and a lack of knowledge of the scope of palliative care. Poor experiences of palliative care due to chronic under funding, may exacerbate these fears.

Changing the law, however, would impact the whole community. The legalisation of euthanasia would be particularly dangerous for the disabled, the mentally ill, and those living with long-term illness. The chronically ill and disabled frequently fear being a burden to others. The existence of legalized euthanasia would increase their sense of burden by putting pressure on them to choose it.

Legal safeguards can never be adequate to protect vulnerable groups. In every country where euthanasia and physician assisted suicide has been tolerated or legalised, the categories of people who can request it has been expanded. Voluntary euthanasia for the terminally ill has been tolerated in the Netherlands since the 1980s. By the 1990s Dutch courts had extended toleration for euthanasia to cases of chronic illness, mental illness, and non-voluntary euthanasia, including children. [4] This continues today. It has been estimated that the majority of euthanasia cases in the Netherlands and Belgium occur without the consent of patients. This has been documented in the following publications:

According to a report published in 2007 the prestigious New England Journal of Medicine, the percentage of non- voluntary euthanasia in the Netherlands occurred four times more than physician assisted suicide. In 2005, the ending of life was not discussed with patients because they were unconscious (10.4%) or incompetent owing to young age (14.4%) or because of other factors (15.3%). [5]

In the Netherlands, the Groningen Protocol allows for euthanasia of newborns. The architects of this Protocol reviewed the 22 cases of child euthanasia that had been reported to the authorities in the seven years prior to 2005 The reviewers concluded that 'most cases are simply not being reported. For all practical purposes, children under the age of 12 in the Netherlands may be euthanized if this protocol is followed, and in the absence of adequate reporting, the practice is largely unregulated. [6]

In summary, over the last 45 years, the Netherlands has experienced the slippery slope where the law and euthanasia is concerned. Over that time the Dutch have moved from judges tolerating the practice of euthanasia for adults suffering unbearable pain to the complete legal recognition of euthanasia even for children as young as 12. In addition there is strong pressure to further extend the legal provision for euthanasia to include children under 12, and for adults over the age of 70 who have become either tired of living or who have come to believe that their life is in all relevant respects 'completed'.

In Belgium there has been a staggering 5,900% increase in reported legal euthanasia cases between legalization (2002) and 2013. The practice was legalized in 2002, and that year there were 24 cases reported. This had increased to 953 cases in the year 2010, 1,432 cases in 2012, and 1,807 in 2013. Add to all of these the cases where terminal sedation is used specifically as a tool for euthanasia (slow euthanasia) then the real incidence of euthanasia in Belgium, as in the Netherlands, is certainly much higher.

Much of the increase in euthanasia practice in Belgium and the Netherlands is influenced by reductions in health care funding, particularly in the area of non-euthanasia palliative care.

The availability of euthanasia or physician assisted suicide at the end of life makes it less likely that palliative care services are funded adequately. Euthanasia is considerably cheaper than palliative care, providing an opportunity for healthcare cost savings to be made at the expense of the welfare of the terminally ill.

There is no reason to believe that the situation in Australia would be any different. It would be highly dangerous to change the current law without fully understanding its consequences.

I would caution strongly against reviewing current Australian law regarding the double effect principle. Doctors are already adequately protected against legal censure when administering pain relief to patients with terminal illness, when the double principle effect principle is applied. I am concerned that a review of the law governing this aspect of palliative care could result in an effective legalisation of active euthanasia.

In summary, I respectfully ask that the Parliament of Victoria works to improve the availability of quality palliative care and chronic pain services to those who need them. I also ask that any move to legalise active euthanasia in our state be strongly resisted, as it will ultimately harm the very people that we wish to protect.

I would be happy to appear at a public hearing if asked. (I will be overseas from August 21 to October 8 2015).

References:

- [1] Palliative Care Services in Australia 2013 Australian Institute of Health and Welfare Canberra tables 7.3 & 7.4
- [2] Palliative Care Australia: letter to Senator Penny Wright 15 August 2014
- [3] The World Medical Association: (Representing 111 National Medical Associations) 'Statement on Physician Assisted Suicide', May 2005
- [4] Fleming, J, "Euthanasia: The Netherlands, and Slippery Slopes", Bioethics Research Notes Occasional Paper No.1, June 1992, Southern Cross Bioethics Institute www.bioethics.org.au
- [5] (Van der Heide et al., 2007 "End-of-Life Practices in the Netherlands under the Euthanasia Act," *New England Journal of Medicine* (5/10), 1960)
- [6] (The Groningen Protocol — Euthanasia in Severely Ill Newborns, Eduard Verhagen, M.D., J.D., and Pieter J.J. Sauer, M.D., Ph.D., *N Engl J Med* 2005; 352:959-962 March 10, 2005 DOI: 10.1056/NEJMp058026)