Submission to Select Committee on End of Life Choices in the ACT

To: LACommitteeEOLC@parliament.act.gov.au    February 2018

From: Malcolm Knight

Introduction
I make my submission as a resident of NSW who has relatives who live near the ACT and receive their healthcare in Canberra and who could be affected by any legislative changes to allow forms of euthanasia. I am also concerned that changes in one state, such as those recently introduced in Victoria, will lead to proposals for other states to follow suit. I regret having unknowingly voted for a senator who subsequently supported euthanasia in Victoria.

I have extensive experience in palliative, medical and trauma health-care and have been with many people at their time of death in a variety of situations. I hope my comments can help to bring some balance to the uninformed and emotive arguments often put forward in the media.

During my time nursing in a palliative hospital, patients reported pain, nausea, incontinence and other discomforts, but we didn't kill them - we relieved those symptoms. Sometimes palliative interventions hastened the dying process, but no one’s life was ended intentionally.

Many people were ready for death – as are some elderly people who are not even ill - but I do not recall any palliative patient saying "kill me now!" The only people I ever encounter seeking immediate death are those who do not have a terminal condition but who have mental health problems.

Perhaps I had a luxury in working in a specialist facility staffed with caring and compassionate professionals, experienced in palliative care. This should not be a luxury: it is what everyone deserves.

Palliative care also involves the patients’ relatives and friends, who almost always come to terms with the dying process when given the right support. Unfortunately, the push for euthanasia is generally driven by people with irrational fears about potential suffering, borne of ignorance as they have not experienced the alternative.

Put simply, there is no need for the deliberate ending of someone's life. Good palliative care already allows for the relief of suffering to take precedence over the continuation of life.
References to “suffering”
People who talk about terminal patients 'suffering' have not experienced good palliative care. It is obvious to me that proponents of euthanasia are more influenced by the idea of a person deteriorating, perhaps to a vegetative state, and that this is distasteful to them regardless of whether or not the terminally ill person is actually suffering.

While just about every terminal condition has a degree of discomfort, palliative care allows for pain and discomfort to be managed far more aggressively than standard pain management.

We don’t kill a person in agony from a broken leg: we provide analgesia to reduce or relieve the pain.

We don’t kill people with gastroenteritis because they are vomiting: we give antiemetics to relieve the nausea.

We don’t kill patients with wounds or sores: we cleanse the wounds and apply dressings.

We don’t kill babies because they are incontinent: we clean them up and make them comfortable and give them love.

We don’t kill paraplegics or quadriplegics because they have lost bodily functions: we help them to make the most of their remaining faculties.

We never used to kill the elderly because they become frail: we helped them with their daily needs and shared in their memories and wisdom.

Talk of physical suffering is irrelevant when almost all physical symptoms can be controlled by various means. Even if there are any real cases where unbearable suffering truly cannot be relieved, then this must still be too rare to justify make sweeping legislative changes. I have never seen such a situation. I have, however, seen many (non-terminal) cases where people suffer because their symptoms are not being managed adequately. These people do not need euthanasia: they need symptom relief. In terminal conditions, they need palliative care.

There is, of course, great potential for emotional suffering with life-limiting conditions. Proper palliative care involves a range of appropriate measures including emotional support, counselling, pastoral care and even medication. There are no other situations where we would consider ending someone’s life, or encouraging suicide, simply because a person is suffering emotionally.

What is finally being acknowledged, at least by some, is that a prime motive in seeking the introduction of euthanasia is the desire to provide individuals with a sense of control over the timing of death, and it has little to do with physical or emotional suffering.

Timing of Death
Pain, in particular, but also many other symptoms are very distracting to rational thought. A patient’s request to end his or her life cannot be regarded as legitimate if he or she is suffering at the time.
The irony in euthanasia is that a person with sufficient mental capacity to make an informed decision to end his or her own life is clearly not at the stage where that request should be acted upon. A person in a state of advanced deterioration, or who is distracted by pain or other symptoms, is highly unlikely to be able to make a rational decision to request euthanasia.

Making decisions in advance has limited value. Consider that people often say they would rather be dead than become – say – paraplegic. Indeed, it is common for new paraplegics to feel suicidal. After appropriate support, however, most paraplegics come to terms with their new life and retract the comments they may once have made.

In other words, we cannot see the future and know how we would actually feel once in a particular situation.

Advanced Care Directives that are now common in aged care facilities are usually written with such open wording that decisions about actual end-of-life care still have to be made at the time rather than in advance.

It also seems likely that a factor in the timing of euthanasia would be convenience. While it might seem like a nice idea to gather special persons together for the actual death, I do not believe that convenience justifies interference with a natural process. Palliative care also allows for the dying patient to spend quality time with loved ones. In any case, is my experience that a dying person will often cling to life until after the relatives have left. I am convinced that most people want to save their loved ones from the distress of watching them die.

“Respect for people’s wishes”
What somebody wants does not necessarily equate to what is best or right, especially given the difficulty in ensuring end-of-life decisions are informed, unbiased and valid. People make poor decisions all the time, often heavily influenced by emotion.

“Dying with dignity”
Talk of dying with ‘dignity’ is a deliberate attempt to imply that dying naturally is not dignified. Patients’ dignity is always preserved during palliative care, and there is nothing undignified about being cared for until the natural end.

We euthanase pets for “kindness”
We euthanase our pets partly because we cannot explain to them what is happening - either in advance or during a terminal condition – but also because an animal’s suffering is more difficult to gauge. Any honest assessment will reveal that cost and convenience are significant factors, as euthanasia is cheaper and easier than lengthy palliative care. I am very concerned when any government would consider euthanasia for humans while quality palliative care remains significantly underfunded.

With few exceptions, we keep pets to bring joy to our lives, not to be a burden. In all measures, we place less value on an animal’s life than we do a human’s. As a society, we need to be very careful to avoid reducing the value of a human life to that of an animal.
Concerns
I often encounter elderly patients who feel they are a burden on their families. It is hard to imagine any euthanasia legislation that would adequately prevent an individual from seeking to be terminated as a noble gesture, whether or not the family appears supportive. Similarly, it seems unlikely that legislation could also guarantee that an individual were not being influenced, even subtly, by relatives with ulterior motives.

Additionally, I am certain it is impossible to ensure that every individual in a terminal patient’s network will be absolutely supportive of euthanasia being applied, both at the time and forever after. Ending a person’s life deliberately will likely always leave the question - at least for some friends, relatives or even descendants - of whether it was done too soon, too late, or should have been done at all.

Suicidal individuals can be very good at hiding their intentions. Traditionally, suicidal ideation has been regarded as a mental health problem. In the euthanasia discussion, suicide is now treated by some as something to be lauded. We have already seen euthanasia legislation fail to prevent assisted suicide in individuals who should have been treated, not terminated.

I am also concerned about the potential for legislation-creep as we have seen with so many other laws. Victoria’s new euthanasia legislation – arguably enacted in the wrong environment, by extremely fatigued ministers – is already regarded as weak by proponents of even stronger euthanasia legislation. Overseas, we are seeing legislative changes allow younger and less unwell persons to suicide than had been allowed under those countries’ original euthanasia laws.

Conclusion
Euthanasia of humans cannot rightly be considered while good palliative care is not available to everyone, and while the public is generally uninformed about the process and benefits of palliative care.

Euthanasia must never be an option except in the unlikely event where the person is already in the care of an experienced palliative care team and that team is convinced that the patient’s physical suffering cannot be relieved by any means other than death.

Fraught with enormous potential for error and abuse, euthanasia legislation is mainly about allowing perfectly healthy individuals a sense of control over imagined suffering, and it is best avoided.

We can do better for our terminally ill than simply to end their lives early.

Malcolm Knight
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