Submission Cover Sheet

End of Life Choices in the ACT

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I am sure there are many thousands of examples of people suffering from a terminal disease, who have no quality of life, and are in much pain for months before they die.

I would like to present three examples of people I knew who were in this position and the only way out was to suffer a cruel end by starving themselves to death.

Surveys demonstrate that about 70-80% of the population support euthanasia. I am guessing many of those who do not support euthanasia are young people with no health problems or people with strong religious views.

My mother was in poor health in an aged care facility for over two years and for most of this time was in a lot of pain. Her mental abilities were good but physically she was a wreck. For at least the last 6 months, she was bed-ridden, was deaf, was blind and was in a lot of pain from acute arthritis and other problems. It hurt every time she rolled over in bed. When I asked the head nurse for more pain relief, she said my mother was already on the maximum pain relief and that any extra would kill her. That is what she wanted. She pleaded with her doctor to give her “the magic pill” so she could die.

She would not eat very little despite the family attempts to encourage her to eat. She admitted she was trying to starve herself. At one stage, she was so ill from not eating, she was taken by ambulance to hospital where her life was saved. She finally succeeded in starving herself to death; a very awful way to die. Her weight shortly before her death was less than 30 kgs.

In the same aged care facility, a lady in a nearby room had a twisted spine and at times called out continuously for up to an hour non-stop “Please, someone help me”. I assume she was on the maximum pain relief available. My mother told me that it was known around the aged care facility that she was starving herself and that finally worked to bring her life to an end.

A third case was a close friend who suffered a stroke. He could not move nor speak. He suffered constant painful cramps. After some months he refused to eat and thus staved himself to death.

That this situation exists is unbelievable.

Safeguards against mentally ill patients, greedy relatives etc can be easily put into place eg proposals that Andrew Denton has put forward. (Attached are some of Andrew’s comments about euthanasia and proposed safeguards).

Palliative care is not available to many people in need. In any case, “it is simply a myth to suggest that palliative care, no matter how many resources it has, can deal with all suffering and distress at the end of life”.

With regard to greedy relatives wanting a person to die to get their hands on their money, the opposite can be the case. I know a person who was in hospital in very poor health but he was an ex-serviceman with all his expenses paid (ie free accommodation, medicines, food etc.). He was receiving a generous pension from his ex-employer as well as government pensions. From a financial point of view, it was best for his beneficiaries to keep him alive no matter what his suffering was.
A well-known heart specialist has written an excellent article (attached), part of which is included below:

*Without wishing to sound crude, I call this the “bum wiping rule”. If another person has to wipe your backside and there is no possibility that this will change and you consider the quality of your life to be miserable or you aren’t in a position to even discuss the issue, it is my view that all medical therapy should be stopped apart from pain relief and sedation. I would administer progressive doses of narcotics placing the sufferer in a peaceful oblivion allowing nature to take its course rapidly.*

*What we have now is many people languishing in institutions such as nursing homes at times for months to years, dying slowly in total misery. This is more the norm than the exception and in my view, society has gone mad to accept its dying citizens being treated in this fashion.*

*There are many people working in palliative care already practising compassionate medicine but often palliative care is not extended to those people languishing in nursing homes.*

We need the decision makers (politicians) to actually get outside their offices and walk around aged care facilities and see for themselves the suffering.

Personally, at age 71, my greatest fear is approaching the end of my life with no quality of life and being in constant pain for a long time before my death. I am sure that this fear is shared by most older Australians.

I think we currently live in a cruel society where many people, living in constant pain and with no quality of life, have little choice but to starve themselves to death.

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David Ward

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The case for compassionate medicine

Article by Dr Ross Walker (Heart specialist and well-known author)

With the recent vitriolic debate in the Victorian parliament and the repeat in New South Wales, I thought I would give my position on the topic of euthanasia.

There are many people who are concerned that once euthanasia is passed then vulnerable elderly people will be prematurely taken off the planet often at the behest of their greedy relatives looking to cash in early on the inheritance. The laws suggested around euthanasia will absolutely prevent this from happening.

But, I do not want to get into a debate about the particular nuances of these laws but would like to give my view on the place of euthanasia in medicine as it stands today. I have no doubt that there are some very rare cases where the only answer is euthanasia and if a person is suffering and their life is miserable, I have no problems whatsoever with assisted suicide.

But, it is my opinion that in most cases this is completely unnecessary and rather than supporting or promoting the practice of euthanasia, it is my opinion that doctors should be practising (which let me say many are doing so under the radar) what I call “compassionate medicine”.

As a doctor, I believe our first and most important responsibility is to relieve suffering. A good doctor relieves suffering, attempts to make an accurate diagnosis and form a reasonable and appropriate management plan for whatever condition the person suffers. I believe we should do everything we can to prolong someone’s life but do nothing to prolong their death.

Most sensible and well-trained doctors can clearly determine in conjunction with the person and their family, when the patient has entered the death phase. The death phase in my view is when a person has a terminal illness with absolutely no possibility of recovering.

This doesn’t just relate to terminal cancer but it also involves end stage Alzheimer’s disease, a severe stroke with a subsequent disability from which there is no reasonable chance of recovery, severe intractable pain for which no reasonable medical therapy is leading to any degree of relief and of course end stage neurologic conditions, such as motor neurone disease.

Without wishing to sound crude, I call this the “bum wiping rule”. If another person has to wipe your backside and there is no possibility that this will change and you consider the quality of your life to be miserable or you aren’t in a position to even discuss the issue, it is my view that all medical therapy should be stopped apart from pain relief and sedation. I would administer progressive doses of narcotics placing the sufferer in a peaceful oblivion allowing nature to take its course rapidly.

What we have now is many people languishing in institutions such as nursing homes at times for months to years, dying slowly in total misery. This is more the norm than the exception and in my view, society has gone mad to accept its dying citizens being treated in this fashion.

There are many people working in palliative care already practising compassionate medicine but often palliative care is not extended to those people languishing in nursing homes.

I’m not suggesting that compassionate medicine will be the answer for everyone but in my view, it is certainly the answer for most of us if we are placed in this situation. It is my view that we will markedly reduce suffering for many people if compassionate medicine becomes the norm not the exception.
Interview with Andrew Denton

He explained it would have "three bedrock principles".

Firstly, to access voluntary euthanasia a person would need to be a "mentally competent adult — excluding children or those with dementia or Alzheimer’s disease", Denton said.

Secondly, the request would be required to be voluntary. And thirdly, the person must suffer from a physical illness, excluding "purely psychiatric suffering".

Denton also told Lateline he believed voluntary euthanasia laws should go hand-in-hand with increased resources and funding for palliative care.

"Palliative care has an incredibly important role in our society," he said.

"However it is simply a myth to suggest that palliative care, no matter how many resources it has, can deal with all suffering and distress at the end of life.

"In their own words, Palliative Care Australia say that even with optimal care they cannot deal with all pain and suffering at the end of life."

Q&A show with Andrew Denton

“The law I propose is a mix of what I found in the States and in Europe. What I have taken from Oregon is what’s called voluntary assisted dying, which is where you are prescribed a medicine by a doctor if you meet certain criteria, which you and only you can take. It is entirely voluntary and that's very important to remember because very often you’re going to hear people say, "Someone has been killed". It is you that takes it.

From Belgium and the Netherlands, I have taken the idea that the entry point to this is what's called unbearable and untreatable suffering and that's a recognition of the fact that that can come in many guises, not just the main diseases that these laws address, which is cancer and heart failure. It can be motor Neurone Disease. It can be a stroke. It can even be chronic rheumatoid arthritis. It can come in many ways. To access this, the very core of it is you have to be a competent adult. If you’re not a competent adult, nothing else happens. You have to convince two doctors independent of each other that your suffering is unbearable and untreatable. All treatment options have to be discussed with you. You have to make an application, both orally and in writing, not once but twice. You have to be offered mandatory palliative or hospice care as part of your treatment. If all these are agreed between you and your doctors and the two doctors, independent of each other, without the family involved in these consultations, I might add, so that there is no possibility of coercion from family members, then you can be granted the right to end your life and then a prescription will be written for you for the medicine which only you can take. If the doctors at any point think that there are psychological reasons driving your request, then they can bring a psychiatrist in to consult.”