



LEGISLATIVE ASSEMBLY
FOR THE AUSTRALIAN CAPITAL TERRITORY

SELECT COMMITTEE ON END OF LIFE CHOICES IN THE ACT

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Submission Cover Sheet

End of Life Choices in the ACT

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Select Committee on End of Life Choices in the ACT: Inquiry into End of Life Choices in the ACT

Submission from the Christian Medical and Dental Fellowship of Australia

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Thank you for the opportunity to make a submission for this inquiry. The Christian Medical and Dental Fellowship of Australia is a national organization with members in all states and territories. It is a fellowship of doctors and dentists and associated healthcare professionals who seek to live as Christians in healthcare.

We are concerned by the current push to legalise euthanasia and physician assisted suicide in Australia both in terms of the impact for our community as well as for our members. We would like to take the opportunity to explain this complex topic by presenting a paper written by one of our members, Dr Megan Best. Dr Best is a researcher at the University of Sydney and the University of Notre Dame Australia and has worked as a palliative care doctor for many years. She is also a trained bioethicist, with appointments at Sydney Health Ethics (University of Sydney) and the Institute for Ethics and Society (UNDA). She is available to answer any further questions you may have on this topic.

The Committee's full terms of reference are to inquire into and report on:

1. current practices utilised in the medical community to assist a person to exercise their preference in managing the end of their life, including palliative care;



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2. ACT community views on the desirability of voluntary assisted dying being legislated in the ACT;
3. risks to individuals and the community associated with voluntary assisted dying and whether and how these can be managed;
4. the applicability of voluntary assisted dying schemes operating in other jurisdictions to the ACT, particularly the Victorian scheme;
5. the impact of Federal legislation on the ACT determining its own policy on voluntary assisted dying and the process for achieving change; and
6. any other relevant matter.

These topics are addressed in order below. However, it is first necessary to define what is meant by EPAS, as there is much confusion in our community about the difference between EPAS and normal end of life care.

Introduction

At the heart of the euthanasia is a conundrum. For over 2000 years it has been a prohibited medical practice. But now? Euthanasia is legal in the Netherlands, Belgium and Luxembourg. Physician assisted suicide (PAS) is possible under legal guidelines in 5 US states, Switzerland and Canada.

In Australia legislation concerning end-of-life issues has been dealt with on a state basis, and euthanasia was legal for brief time in the Northern Territory, from 1995-7.(1) Bills promoting EPAS are regularly debated (and usually defeated) in our state and territory parliaments. As you are aware, the Victorian parliament passed a bill to legalise assisted dying at the end of last year. Bills were defeated in Tasmania, NSW and South Australia.

We're told that 85% Australians are in favour of a change in the law to allow euthanasia, but perhaps less well known is that the majority of doctors (those



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who are expected to actually do the deed) are against euthanasia, and the size of the majority increases as their work is more involved with the dying. All palliative care organisations against it.

So it is worth considering: why are we having this debate now, at a time when we have more medical cures than ever before in human history? The timing suggests it is not a failure of medicine that has prompted this debate. How are we to understand it?

In this paper, I will discuss the definition of euthanasia, because in the community debate, inadequate definitions have been a real barrier in attempts to find clear consensus, and then I will explain community arguments for and against the legalisation of euthanasia before thinking about what's really going on. But let's start by defining our terms.

Definitions

It is no secret that many euthanasia advocates have muddied the waters by bracketing euthanasia with other accepted end-of-life practices in order to increase public support. We need to keep our definitions clear so we all know what we're talking about.

The term euthanasia comes from the Greek – it means 'good death'. However, this is not particularly helpful as both sides claim the advantage of bringing about a good death, and indeed, the question of what constitutes a good death is at the heart of the euthanasia debate. We would all like to see people in our communities dying with dignity and without suffering. The question is, how do we go about achieving this?



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I define euthanasia as ‘an act where a doctor intentionally ends the life of a person by the administration of drugs, at that person’s voluntary and competent request, for reasons of compassion’. The key points to note are that it is an intentional act by a doctor, motivated by compassion. It is a decision made voluntarily by the patient, with no coercion involved, and they are mentally competent at the time. I prefer to keep the definition narrow, so we can evaluate each end of life scenario individually.

I define physician assisted suicide as ‘the situation where a doctor intentionally helps a person to commit suicide by providing drugs for self-administration, at that person’s voluntary and competent request’. The doctor is thus distanced from the act, but morally it is no different to euthanasia as the motivation, intention and outcome are the same. Generally bills that allow PAS will also allow euthanasia if the patient is physically unable to self-medicate.

We also need to be clear on what euthanasia is not.

Euthanasia is sometimes confused with cessation of treatment which aims to prolong life. In life-threatening illness, treatment initially aimed at cure may become futile (no longer working), or so burdensome (such as due to distressing side-effects) that any benefit from the treatment is no longer worthwhile. At this point the treatment may be no longer prolonging life so much as prolonging the process of dying. At this time a decision may be made to stop, or not to start, such a treatment. This practice is not euthanasia because the intention is not to kill the patient, but to allow the underlying disease to take its course. Full supportive care will remain in place so the patient is kept comfortable.



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In the same way, taking someone off life support is not euthanasia. It's not flicking the switch that kills the patient, it's the underlying disease that does it, that's why they were on life support in the first place.

Another situation which is often confused with euthanasia is adequate symptom control in the terminally ill. Very occasionally in the terminal stages of disease the distressing nature of a patient's symptoms may require the careful sedation of the patient, while seeking to preserve their dignity. It is not euthanasia because the intention is not to kill the patient, but to alleviate their distressing symptoms.

Some people would call this practice of symptom control passive euthanasia because of a myth in the community that use of morphine shortens the life of the patient. They argue that if we already practice that type of euthanasia, there is no reason not to practice the other type of euthanasia, using lethal injection, which they call active euthanasia. You see the problem.

Philosophers have spent a lot of time talking about the principle of double effect in order to justify analgesia use at the end of life, but it really isn't necessary. It's all based on a myth – that morphine kills the patient.

This myth has been around for years, and we don't seem to be able to squash it. It makes people scared to use what is an excellent treatment for pain. But in fact morphine in therapeutic doses does not shorten life. Indeed, it may actually prolong it. An Australian study (2) showed increased survival of palliative care patients on high doses of morphine, probably because they were less uncomfortable.



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Stopping futile and burdensome treatment and maintaining adequate symptom control are good medical practices at the end of life and should be encouraged in clinically appropriate situations. When the public has a better understanding of end-of-life care it reduces the call for euthanasia because there is less suffering experienced along with an increased sense of control for the patient.

Arguments for and against euthanasia

The primary arguments for euthanasia in Australia are:

- Euthanasia is a compassionate response to the suffering of the terminally ill which is perceived (often wrongly) to be otherwise unrelievable.
- Euthanasia is an expression of autonomy, that a competent individual should have the right to make self-governing choices, especially in the face of increasing support for euthanasia in public opinion polls.
- It is also suggested that we need to regulate existing euthanasia allegedly taking place underground – no evidence has been given, but anecdotes suggest that it probably does happen.

We don't often hear the arguments against euthanasia in the media, but in summary they are:

- That the sanctity of human life forbids it.



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- Euthanasia is unnecessary due to the availability of palliative care to relieve suffering in the terminally ill.
- There are negative social consequences of legalising euthanasia.
- There is danger of abuse due to the slippery slope which is created with the legalisation of euthanasia.

These arguments will be addressed as I go through the points raised by the inquiry.

1. Current practices utilised in the medical community to assist a person to exercise their preference in managing the end of their life, including palliative care

It is true that many people experience pain and suffering when they are dying, and this has led to a situation where too many of us have seen someone die badly. Maybe this is the experience of members of the committee.

This should not happen, but it still does and is an important factor in the call for the legalisation of euthanasia. It has been the experience of many people campaigning most strongly for the cause. We must do better.

One thing that can completely change the end of life experience is involvement of palliative care. Palliative care is specialised care for dying people, which aims to maximise quality of life, and assist families and carers during and after the death. Its intention is to liberate patients from the discomfort of their symptoms,



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and neither hastens nor defers death. (3) An old slogan for palliative care was, 'we will help you live until you die'.

Currently, only about half of those people in Australia who would benefit from palliative care, receive it. Why is this? One reason is that the modern palliative care movement is relatively new. While students now receive training in pain control, there are many doctors in the community who are not aware of what can be done. The discovery that different types of pain respond to different treatments has revolutionised care of the dying. However, pain control techniques can be taught, and the world health organization has developed a pain relief ladder that all doctors can learn to use, if they are taught. (4)

Furthermore, there are certain demographic characteristics which reduce access to palliative care in the community - low income, non-urban location, acute care settings and nursing homes, ethnic or indigenous background, very old or very young age, and non-cancer diagnosis. More government funding is needed to fill the gap. (5)

Interestingly, one response to the brief legalisation of euthanasia in Australia was a temporary increased injection of funds into palliative care services by the federal government. Since then, the argument for euthanasia on grounds of unrelieved suffering of dying patients has become much less prominent. I'm not saying palliative care is the panacea for all problems at the end of life, but that there are alternatives to euthanasia in terms of end of life care of which the public is often unaware. As the European association for palliative care states in their position statement

On euthanasia, 'our challenge is to transform our care of the suffering and the dying, not to legalise an act which would all too easily substitute for the



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palliative competence, compassion and community that human beings need during the most difficult moments of their lives.’(6)

It is interesting to note that, although advocates of EPAS infer that this represents a peaceful death, in fact research shows that up to 25% of cases are complicated by problems such as patients vomiting, taking medication and waking up after a period of unconsciousness and difficulty administering medication. (7, 8)

Suffering

We also need to recognise that suffering is not merely a medical problem but an existential problem which extends beyond physical pain. It is influenced by psychological, cultural and spiritual factors. The physical symptoms can be dealt with but the suffering may well remain. (9)

Diagnosis of life-threatening disease is recognized as a common precedent to suffering and is recognized as a trigger for the raising of existential questions, which require the patient to seek meaning in their experiences. The arrival of awareness of one’s own imminent death can be difficult to process in a society which is youth-obsessed and death-denying. We don’t know how to die properly anymore. We are uncomfortable discussing it and we have lost our traditions in the west. I think we could be trained to die by example, but few of us have seen examples. Most members of the public have never seen a corpse and many people have long ignored the existential dimension before facing these questions themselves. They’re unprepared, and they’re scared.

In our community the fear of dying is promoted by numerous media accounts of pain and misery experienced as life draws to a close. There seems to be a



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desire in some people to go from a state of health, straight to a state of being dead, without having to “die” at all. In a society which has lost touch with the meaning of suffering, there is also, understandably, a loss of the willingness to endure it.

Currently research into existential suffering at the end of life is in its early stages, but we have established that spiritual wellbeing is as important as physical wellbeing for quality of life in cancer patients. That is, a cancer patient can enjoy a good quality of life despite deteriorating physical condition if their spiritual wellbeing is high. And we are finding effective ways spirituality can be supported in the healthcare setting. I think one of the reasons why involvement of palliative care services is helpful is that consideration of patient spirituality has always been a part of palliative care

Dying as part of life

One thing we in medicine haven't done well in the euthanasia debate is to articulate what is good about the natural dying process.

When a person is dying, he and his family find themselves in a crisis situation. Help may be needed to deal with things like guilt, depression and family conflict, but in this time of crisis, there is the possibility of resolving old family problems and finding reconciliation. The time between diagnosis of a terminal condition and death is often a time of great personal growth. Peace can be found by mending broken relationships. I have seen this time and time again. Those at the coal face know very well that patients can and do choose the moment of death as a natural act if good care is available. Most deaths in our unit are peaceful, where someone slips away while their family sits by. I think the public would be comforted by hearing some of these stories.



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2. ACT community views on the desirability of voluntary assisted dying being legislated in the ACT;

On behalf of our ACT members, we would like to acknowledge that the loudest argument for EPAS that we hear in the community is that of autonomy: the principle of self-determination, expressed here as the right of the individual to choose the timing and manner of their own death. Even though we all give lip service to suffering, the real push for euthanasia comes from a desire for autonomy – the right to choose. We think this was quite clear in the Victorian debate also.

If the argument were about suffering, we would not have the Greens calling for cut in funding for palliative care services who say they won't co-operate with any euthanasia laws, we wouldn't be having this conversation now, at a time when medicine is so advanced, and it wouldn't feature just in western countries.

It's all very well to say that 85% of Australians are in favour of euthanasia, but most of them are probably quite healthy. You see, while many people say that when they are facing death they would want to be able to request euthanasia, the proportion of people actually requesting it when facing death is very different. A study done in Sydney (10) has shown that only 2.8% of patients in a palliative care service requested euthanasia when first seen. After palliative care commenced, this number was reduced to less than 1% of those referred. Personally, I am not surprised by these low numbers. In my experience, people at the end of life are more likely to want more time, not less.

And what do we know about actual euthanasia requests in the jurisdictions where it is legal? Usually they are not related to physical factors but to psychosocial and existential factors. Things like the fear of death and loss of



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control, fear of becoming a burden and of loss of dignity, anticipated problems rather than current problems, fear of the future, fear of being left alone.(11)

Research in Canada shows that patient desires are known to fluctuate over time, including desires for hastened death.(12) that suggests that even if patients sincerely request euthanasia, they may have changed their mind if we had given them more time.

This research also found that when patients expressed their fears at the end of life it was often misinterpreted by healthcare providers as a request for euthanasia when it was really intended to be a cry for help.(13) When a patient says they wish they were dead, it doesn't necessarily mean they are asking you to kill them. We all have bad days.

The incidence of depression in cancer patients has been measured as high as 45%. Desire for hastened death is a symptom of depression. In any other group, a request for death would alert a doctor for urgent psychiatric review: why is this group of patients being treated differently?(14)

And finally, if the suffering the patients wish to avoid is due to existential concerns, then it is not only patient autonomy, but also the social, psychological, religious and cultural concerns that need to be addressed.(15)

But given that some people do still request euthanasia, how do we proceed? I will return to this point after addressing the points about risks of legislation.

3. Risks to individuals and the community associated with voluntary assisted dying and whether and how these can be managed



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Arguments supporting EPAS laws presuppose a world of ideal hospitals, doctors, nurses and families. But we don't live in an ideal world. We live in a world where humans make mistakes about prognosis and have selfish motives. The prospect of inheritance sadly brings out the worst in many people. We see this regularly in our practice of medicine. For this reason, legalisation of euthanasia holds a number of risks.

Elder abuse

In June 2017, the Australian Government Attorney-General's Department launched the Australian Law Reform Commission's report on elder abuse. (16) It found that elderly persons are victims of financial fraud. It recommended that a national register of enduring powers of attorney be established to prevent greedy children from using the document as a "license to steal" from their elderly parents. The paper notes that "the potential for pressure and coercion in setting up the instruments" [the powers of attorney appointing children to act on their parent's behalf] and that "early inheritance syndrome" is on the rise. "With Australians living longer than ever before, the ALRC inquiry heard many examples of children who were impatient to get their hands on their parents' money and tried to claim their inheritance before they were entitled to it."

We cannot be sure that euthanasia, once legalised and socially accepted would remain voluntary. Vulnerable and burdensome patients may be subtly pressured to request termination of their lives, even though they don't really want to.(17)

Another risk is that doctors may not be able to resist the extension of euthanasia to those who don't, or can't, consent to termination of their lives. Proponents of euthanasia will tell you that legal guidelines will prevent this



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happening. But if you examine the jurisdictions where euthanasia has been legalized, you can't be so sure.

The Netherlands

In the Netherlands, euthanasia was legalised in 2002 after 20 years of widespread practice under legal guidelines. By the time the law had passed, the courts had already legitimized the death of patients who were not terminally ill. Adolescents aged between 12 and 18 can be killed with the consent of their parents, and early in 2005 a Dutch hospital published their guidelines in a medical journal on how to kill disabled newborns.(18) Under this amendment of the law, it is not only the anticipated suffering of the child that is taken into consideration, but also anticipated suffering of the parents can justify its use. The Dutch are currently debating whether euthanasia should also be allowed for children 1-12 years old, as is the case in nearby Belgium. They are also debating the need to allow the elderly to be euthanased when they are 'tired of life'.

Are these the values we want to pass onto our children? That suicide is a reasonable response to hardship in life? In the Netherlands, unassisted suicide rates have risen to an all-time high.(19) Laws, once passed, have an educative influence – they mold social attitudes.

We don't have to have the current media circus of who says what about the safety of the euthanasia practices overseas. It has been documented in Dutch government records so there is no confusion.

In July 2012, esteemed medical journal, the Lancet, published an analysis of euthanasia and end-of-life practices in the Netherlands from 1990 to 2010.(20)



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It indicated that in 2010, [23% of the euthanasia deaths](#) were unreported in the Netherlands. However, despite this omission, there was a clear increase in the proportion of euthanasia deaths over the time studied, including dementia patients who died under the legislation. Of more concern, there has been an increase in the number of hastened deaths without discussion between the doctor and the patient, their family or other physicians. Regular surveys have shown that around 1,000 patients a year are killed without their knowledge or consent. We ignore the lessons of the Netherlands at our peril. These abuses should warn us against naïve enthusiasm about proposals to decriminalise euthanasia.

Oregon

The Victorian legislation is said to be modelled on the US state of Oregon's *Dying With Dignity Act 1998*. This is reported by the Andrews' government as being a 'safe' option. This law provides for medical practitioners to prescribe drugs for self-administration by a person to allow the person to end his or her life when suffering from a serious and incurable condition which is causing enduring and unbearable suffering that cannot be relieved in a manner the patient deems tolerable.

The Oregon government releases very limited reports each year which do not give full information regarding what happens at the time of death. However, they have shown that, rather than protect citizens from risk of harm, the current system allows for regular abuse. For example, the annual reports show that the main reason people requested EPAS was not because of suffering but because they were concerned about being a burden. (21) There is inadequate screening for mental health problems, with 1 in 6 patients dying under the law showing



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features of clinical depression. (22) The incidence of EPAS is increasing steadily each year since the bill was enacted. (21) And while under the legislation EPAS should only be available to people with a terminal disease with death expected within six months, some people have lived over one or two years before ingesting the lethal substance, which demonstrates the error in prognosis made by their doctor. (23) Finally, there is no independent evidence that the person took the lethal medication voluntarily. Once a person has the lethal medication in their home, there is no way to police whether they took it when they decided to, or whether it was administered under duress, surreptitiously or violently. Once such medications are made available in the community, it is difficult to police them.

4. The applicability of voluntary assisted dying schemes operating in other jurisdictions to the ACT, particularly the Victorian scheme

As the Victorian scheme is based on the Oregon model, it is fair to say that we think the dangers to the general population make it too dangerous to contemplate.

So where does that leave us? Let's take a minute to think about the public debate.

The people who initially speak up are those who want change. Those who are happy with the status quo are often caught unawares and are less organized, or lack the impetus to fight for what they already have.

Furthermore, Australian media tends to dumb down ethical arguments so that even if they aren't biased, we are left with a simple choice between a and b, and all the nuances of a debate tend to be lost.



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Add to that, in the Australian media, the conservative voice is usually dismissed as anti-progress without a decent hearing. In the euthanasia debate it is notoriously difficult to be heard if you are anti-euthanasia, which leaves the public debate unbalanced.

And the public debate *is* unbalanced. We don't hear the narratives of the vulnerable patients, those who can't go on to 'Q & A' to talk passionately about their vulnerability and experiences of coercion.

Another problem in the euthanasia debate is that we tend to focus on the wrong question.

The public debate is about whether we should change the law to allow euthanasia, not about whether euthanasia is right or wrong for individual cases. Euthanasia is going to be ethically defensible within the ethical framework of some individuals whose morality recognizes autonomy as a priority. Obviously it can be argued this way on an individual basis. If you thought that this world is all there is and living has become unbearable, the choice to end it all makes sense.

But it is not as easily justified when you approach it from a societal perspective.

From the community perspective there is a tension here between those people who rationally request euthanasia and the vulnerable people who would be at risk of being killed against their will, as is happening now in the Netherlands. Autonomy- the freedom for the individual to determine the timing and manner of their own death versus security the freedom of the community to live within the protection of the larger society. How are we to resolve this? This is an example of an ethical dilemma where values conflict. Incommensurable values that



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cannot be measured against each other. Is there a right to die that the government should support?

While legally a man is free to end his life when he chooses, that does not mean he has a right to do so, and he certainly does not have the right to compel someone else to kill him. I would suggest that we do need to respect autonomy, but not as an absolute. People are more than autonomous entities. The argument from autonomy is based on a view of human beings which is too shallow, and devoid of the inevitable social context. Anyway, someone's autonomy is going to be compromised- be it the one who wants to die and can't, or the one who wants to live and dies.

So, how should our society approach the euthanasia problem?

There are several ways it could be done.

1) We could look at the experience of those who have legalized euthanasia, as we have just done, and say that we cannot ensure that any safeguards would avoid abuse. This is the conclusion of government-sponsored enquiries in England, the USA and Australia.

2) In view of the very small number of people demanding euthanasia, we could say that we must err on the side of security and the responsibility of our society to care for the larger group of people who cannot care for themselves.

Of course, this means that those demanding euthanasia will not have what they want and that is terrible for them, but we must protect the frail and vulnerable who want to live. People like my patients in the palliative care clinic.

Proponents of euthanasia bills will reject this reasoning. They keep saying that it only affects patients and their carers, but this is just not true. It can't be.



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Legalisation of euthanasia must affect society as a whole because in legalising euthanasia we are changing one of the most basic tenets of our society. That is, that we do not kill each other, even for reasons of mercy and compassion.

3) But in fact what has happened in Australia is that the active minority have pushed past the question of whether we should legalise euthanasia, to how we should do it – these questions were reformed about 2 years ago.

And now euthanasia will soon be available to people in Victoria.

I have made a study of suffering in my medical research and there are ways to make a difference for those at the end of life. Everyone needs to understand the meaning of their life before they can peacefully let it go.

The euthanasia debate is an expression of a society that is struggling to find meaning in life, and so finds no meaning in death. It is desperately trying to control death any way it can. But the ultimate answer to our plight as we struggle on in this broken, fallen world is not legalisation of euthanasia. Let's help those who suffer find a way through the suffering so they can die in peace.

Megan Best 2018

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