

EUTHANASIA

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 euthanasia and physician-assisted suicide are regularly debated in our state parliaments. Andrew Denton has just jumped on board. It just never stops.

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 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 my question is this: why are we having this debate in Western countries 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 essay 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 why so many palliative care workers oppose a change in the law to allow 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?

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 – therefore in this essay, the terms are used interchangeably.

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.

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.

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

Now we know what we are discussing, what do we hear in the public debate?

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.

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.
- 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.

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 your experience.

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, and neither hastens nor defers death. 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. 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.

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 palliative competence, compassion and community that human beings need during the most difficult moments of their lives.'⁽³⁾

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.⁽⁴⁾

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 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.

Dying as part of life

I think that 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.

Autonomy

But the loudest argument for euthanasia 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.

Well, 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(5) 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 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.(6) Research in Canada shows that patient desires are known to fluctuate over time, including desires for hastened death.(7) 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.(8) 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 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?(9)

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.(10)

But given that some people do still request euthanasia, how do we proceed?

Risks of legal euthanasia

Arguments supporting euthanasia 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 brings out the worst in many people. For this reason, legalisation of euthanasia holds a number of risks.

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. Remember that fear of being a burden?(11)

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

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. It is legal to kill

patients who are not mentally competent. 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 The New England Journal of Medicine on how to kill disabled newborns.(12) 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.(13) Laws, once passed, have an educative influence – they mould 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, The Lancet published an analysis of euthanasia and end-of-life practices in the Netherlands from 1990 to 2010.(14) 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.

We ignore the lessons of the Netherlands at our peril. These abuses should warn us against naïve enthusiasm about proposals to decriminalise euthanasia.

The public debate

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.

Add to that, in the Australian media, the conservative voice is usually dismissed as anti-progress without a decent hearing. The conservative voice of the church especially so. 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 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.

There are several ways we could approach this problem.

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.

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.

This is where we are at the moment.

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. 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.

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 we need to push back against the tide. We know that life has meaning, and death has meaning. And when you start to follow-through on the idea that some lives are not worth living it puts the most vulnerable in our community at risk. Surely a society is measured by how it treats its most helpless citizens.

We must speak up and let our politicians know that there are citizens of Australia who do not support a change in the law to allow euthanasia. Because, in the end, when we don't agree, there is a vote. He with the most votes wins. We are not pushing our values on to others when we contribute to public debate, we are using our democratic prerogative to voice our own views and caring for those who cannot care for themselves.

So what can you do?

Write letters to your local MP.

Write to the newspapers.

Write submissions to parliament.

Talk to your friends and family.

Euthanasia is not inevitable.

Unless we do nothing.

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