Euthanasia: are the risks too great?



From the Minority Report by Daniel Mulino MLC to the Victorian Legislative Council Inquiry into End of Life Choices, June 2016

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Debate about legalising euthanasia and assisted suicide continues to rage in most states of Australia.

The Victorian Legislative Council established an Inquiry into End of Life Choices in May 2015, and issued its final report in June 2016.[1]

A majority of the committee members who conducted the inquiry recommended, among other things, that assisted dying be legalised in certain limited circumstances.[2]

Daniel Mulino MLC, one of the two members who disagreed with this recommendation, has issued a comprehensive minority report that considers the evidence in some detail. Here is an edited extract.

Extremely complex situations can arise

Not all pain can be effectively managed, whether physical or psychological. In the face of unmanageable pain, some people express a clear desire to end their life.

For most of us, witnessing great suffering by another person, particularly a loved one, prompts a strong desire to find a way to end that suffering. That is why many of the people who have a desire and willingness to give assistance to these wishes do so out of compassion and love.

But situations involving unendurable suffering are not limited to the end of life. They can arise as a result of non-terminal diseases, accidents or other changes in circumstances that have ongoing negative consequences on a person's quality of life.

The euthanasia and assisted dying debate generally focuses on cases occurring near the end of life, since these are widely seen to provide the strongest support for legal intervention to give effect to a person's wish to die.

Individual autonomy is not an absolute right

It is almost universally agreed that adults have a right to make informed choices about their medical treatment, including opting for a withdrawal of treatment. This minority report supports that proposition.

But euthanasia and assisted suicide are different. They are not simply a matter of whether to give effect to an individual's choice about their own treatment. They necessarily involve third parties, usually medical practitioners, in acts that will intentionally result in death. As such, acts of euthanasia and assisted suicide move from the private realm into the public realm.

Adults have a right to control what happens to them. This includes a right to decide which medical treatments are administered to them and a right to have medical treatment fully withdrawn should a person decide that the burden of any treatment would outweigh the likely potential benefits.



Care – not killing

A patient should be able to convey a desire to have treatment withdrawn either explicitly while conscious or through a clear statement of their preferences that could take effect should a person fall into an indefinite unconscious state.

But it is not enough to assert an individual's right to autonomy in cases of euthanasia and assisted suicide, since the ethical dimensions are more complex. Any system of regulated euthanasia or assisted suicide must involve the active participation of members of the health profession and possibly also other regulatory arms of the state.

The role of professionals in a regulated euthanasia or assisted suicide regime could take a number of forms, including some or all of the following:

- One or more medical professionals providing approval before an individual is granted access to either euthanasia or assisted suicide.
- One or more medical or related professionals providing counselling before either euthanasia or assisted suicide is administered.
- One or more medical professionals (or a chemist, with approval) prescribing the drug/poison to be used in an assisted suicide.
- One or more medical professionals administering euthanasia.
- Medical professionals or others as deemed appropriate witnessing an assisted suicide.
- Medical professionals and others as deemed appropriate monitoring instances of euthanasia or assisted suicide and possibly hearing appeals at different steps of the regulated process.

Euthanasia and assisted suicide involve broader policy questions in relation to how the medical system can best work in the interests of individuals who are either terminally ill or in grave physical or mental distress. Issues such as unintended consequences, and whether procedural breaches can be managed, lie at the heart of the issue.

In giving evidence to the House of Lords Select Committee inquiry into the Assisted Dying for the Terminally Ill Bill, Professor Alan Johnson, Emeritus Professor of Surgery at the University of Sheffield observed:

> the impression has been given that obeying patients' wishes is the overriding ethical imperative for doctors. Of course it is important, but it is not paramount. If it were, I would have done many unnecessary operations and some harmful operations in my time as a surgeon (Q 165).[3]

He cited as an example, the refusal of doctors to prescribe antibiotics at a patient's request for relatively trivial conditions because to do so would "produce resistance which might have quite a serious effect on people further down the line".[4]

Consequences for vulnerable people

The Select Committee concluded: "We are agreed that patient autonomy cannot be absolute and that there must be some limits set, in the interests of the wider community."[5]

In the context of euthanasia and assisted suicide, there is arguably a gain from giving effect to some patients' wishes to hasten their death. But this must be weighed against the potential for societal harm through a range of potential negative consequences, including:

- vulnerable people being pressured into euthanasia or assisted suicide;
- people having their death hastened without having given proper consent; and
- a gradual broadening of practices without transparent public consideration.

Evidence from jurisdictions that have legalised euthanasia and assisted suicide shows that all of these are real risks.

The *Majority Report of the Victorian Legislative Council Inquiry into End of Life Choices*[6] gave considerable weight to the evidence from the Coroners Court of Victoria. This evidence included details of some confronting situations in which people committed suicide, often in very distressing ways, in order to end suffering.

However the Majority Report fails to point out that many of the instances raised by the Coroners Court would not fall within the scope of its proposed regime for legalised assisted suicide.

We do not face a choice between respecting autonomy and bringing dubious actions out of the shadows on the one hand versus an intransigent, knee-jerk protection of the status quo on the other. Rather, we face a choice between two imperfect situations. In neither will the wishes of all people to die be fully complied with. In neither will there be full and transparent compliance with the law.

The choice as to whether or not to legalise euthanasia and/or assisted suicide should be guided by an informed judgement of the likely consequences for our overall treatment of people in vulnerable situations.

Only a tiny minority of cases

While not all pain can be managed, it can be managed in the vast majority of cases. The proportion of cases in which pain can be managed is constantly increasing. Experts in palliative care, oncology and related fields almost unanimously agreed that nearly all symptoms arising from physical pain at the end-of-life can now be managed.

The palliative care and oncology experts who gave evidence to the Victorian Legislative Council inquiry stated that, over long careers, the number of people expressing a desire to have their life shortened was very small.

Even where there is an expressed desire to die, it is critically important to understand the nuances of such requests. Where the person making the request is experiencing depression or a mental illness, which is relatively common, there are usually other treatment options worth exploring. Holistic palliative care and other forms of assistance can often provide effective relief, even if not complete, and can often lead to a reversal in the expressed desire to die.

In almost all cases where a patient experiences a great deal of pain, including terminal cases, the symptoms of that pain can be managed by current best practice in pain relief and palliative care. It is important to note that the capacity of health practitioners to manage the symptoms of pain is increasing over time.



Pain relief is effective in almost all cases

A number of expert practitioners in palliative care gave evidence to the inquiry, including Associate Professor Daryl Jones of Austin Health, who said:

> in 20 years as a clinical practitioner, the number of patients I have seen who die to whom that applies is the overwhelming minority.[7]

Associate Professor Peter Hunter, Geriatrician and Director of Aged Care, Alfred Health said:

> We do know that in almost all patients, if we do a proper assessment and understand that the drugs are available, we can alleviate pain and we can do a good job of that.
>
> I have never not been able to control anyone's symptoms around pain once you have got them on the right treatment path, be it narcotic analgesia or infusion pumps et cetera, so I think that if anyone dies in pain, that is an absolute travesty, because there is capacity to really manage that effectively in this day and age.[8]

Moreover, the proportion of patients for whom pain is manageable is rising. When asked if palliative care techniques had improved, Dr Michelle Gold, Director of the Palliative Care Unit at the Alfred Hospital stated:

> There are always new medications available in that sense. We are having increasingly fruitful interactions with some of our interventional colleagues to provide pain relief with various procedures and interventions that are sometimes much better directed than the medications are and hopefully have fewer side effects. It is terrific that there are new techniques – new ways of delivering some of the old medication.[9]

Knowledge about options can provide comfort

Many health practitioners spoke of the considerable potential to provide patients with peace of mind by clearly communicating the pain relief options available to them. For example Ms Deidre Bidmade, Vice-President of the Warrnambool and District Community Hospice, said:

> in the last 10 years the biggest factor when somebody is dying is, how I am going to die? Is my pain going to be out of control?
>
> These conversations before somebody is in their last phase of dying is so important, because if you allay those fears and reassess the fact that we have such wonderful drugs out there to ensure that people are not in pain and that we do have things like Niki syringe drivers, so that you can go home with that in situ and that can be titrated to the needs every day, if you can give people peace of mind that they are supported in the journey and that there is no need for acceleration of symptom, that in my experience has been most of the underlying issue.[10]

Associate Professor William Silvester, President of the International Society of Advance Care Planning and End of Life Care, said:

> I am amazed by the number of times that I have gone to walk away and someone has called me back and said, "Look doctor, I didn't tell you, but in fact I've been thinking about euthanasia, and now that you've been able to lift such a weight off my shoulders and I can now be sure and confident that I am going to get the care that I want at the end in the way that I want it, I can now concentrate on living as well as possible.
>
> "I don't have to think any longer about getting Nembutal or saving up all of my prescription tablets or whatever so that I can do something before I lose control,

because now I can see that even when I reach a point where I no longer have control, I will still get what I want and I will not get what I do not want."[11]

Dr Ranjana Srivastava recently wrote an internationally acclaimed book, *Tell Me the Truth*, dealing with the meaning of a good life and good death and the ethics of end-of-life interactions. She is an oncologist with considerable experience and adjunct associate professor in the Monash University Faculty of Medicine, Nursing and Health Sciences. She said:

> from 15 years of experience … in all my career there have been no more than two or three people at most, in the thousands of patients I have seen, who have said, "I have had enough. I want to die."[12]

This was corroborated by other evidence, including from Professor Peter Hudson, Director of Palliative Care at St Vincent's Hospital, who said:

> We have been collecting data in two large teaching hospitals for about 15 years now, and it shows that less than 1 per cent of patients referred to the palliative care consultation service actually request euthanasia.[13]

Even where people ask to die or ask to be killed, the subtle nuances in what they are communicating can only be interpreted by an expert. Dr Natasha Michael, director of Palliative Care, Cabrini Health, said:

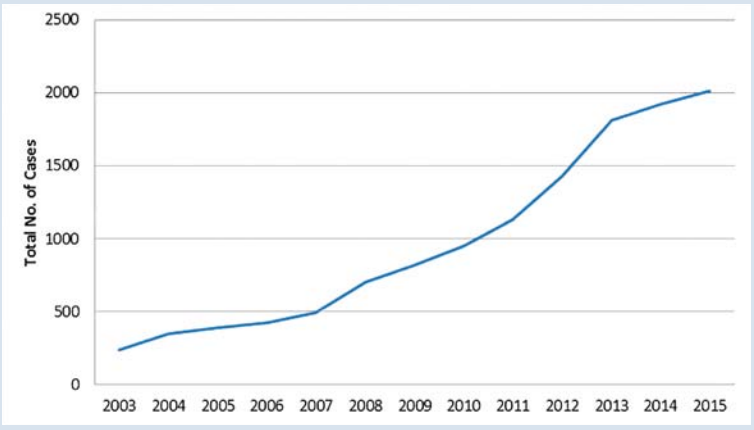
> One of the questions I am always asked is: do patients ask you to kill them? The answer is: yes. I do not use the term "request for euthanasia"; I use the term, "They express a desire for death". Many might have heard me use this terminology or expression before.
>
> People say one of three things to me: "I want to die", "Let me die", or "Kill me". The people who are saying "I want to die" are people who are saying: "My suffering is so unbearable at this point in time, with my pain, my distress or the burden I am placing on my family, death has to be a better option."
>
> The answer to that is not injecting them with a drug or providing barbiturates: the answer to that is saying, "How can I help you with these factors that are making you feel that death has to be the better option?"
>
> The "Let me dies" are saying, "You know what, I have fought this fight. I have run the course. I am 85 – or I am 63 – I have had six lines of chemotherapy. I have had enough. Let me die". *The "Kill me" is from a really, really small minority.*
>
> Most health professionals are not trained to unpick these things. They lump them together in a singular cohort, so you think of the danger you pose when people come to you and express a desire for death when actually what they are saying is, "My suffering is so unbearable that I just want you to help me". The risk is phenomenal.[14]
>
> If you have an unskilled practitioner, you do not have the ability to distinguish these complex psychosocial [phenomena]. The risk is too high … I have seen too many people express a desire for death when actually all they are asking for is help.[15]

To set up a system in which many GPs face a situation in which they have to interpret complex end-of-life situations will create significant risks particularly given that most GPs do not have training in this specific area of care and will face such situations rarely. These risks are further compounded by the inadequacy of safeguards in practice.

For the vast majority of people, modern pain relief and palliative care can manage physical pain right up to the end of life. If euthanasia or assisted suicide is legalised so as to deal with this type of situation, one would expect to see a small and relatively stable number of cases over time. But in every major jurisdiction that has legalised euthanasia or assisted suicide, the number of cases has grown rapidly.

Psychological pain is sometimes more difficult to manage than physical pain. However, once psychological pain is used as a rationale for euthanasia or assisted suicide, difficulties arise – since this type of pain is not particularly associated with end-of-life issues.

It can therefore be used to justify the extension of euthanasia and assisted suicide regimes to non-terminal situations. Moreover, allowing euthanasia or assisted suicide in cases involving profound psychological pain is problematic, since the patient's condition will likely impact on their capacity to provide consent.



Belgium: increase in euthanasia cases, 2003 – 2015[16]
Compound annual growth rate: 19.6%

Numbers continue to soar

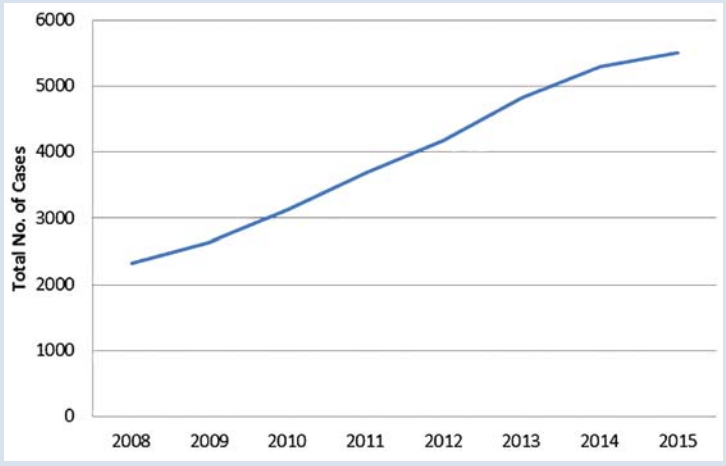
In all major jurisdictions where euthanasia and assisted suicide is legal, the number of cases is growing rapidly. This has been occurring for almost two decades in some places, with no sign of abatement. The majority of this increase is not due to the aging of society or to a growing awareness of end-of-life options. It is most likely to due to factors such as:

- An expansion in the categories of people eligible to opt for euthanasia or assisted dying, either through formal legislative change or, sometimes less transparently, gradual changes in the interpretation and application of existing provisions.A "normalisation" of euthanasia or assisted dying in the medical system and across the broader culture.
- Systemic failures in safeguards.

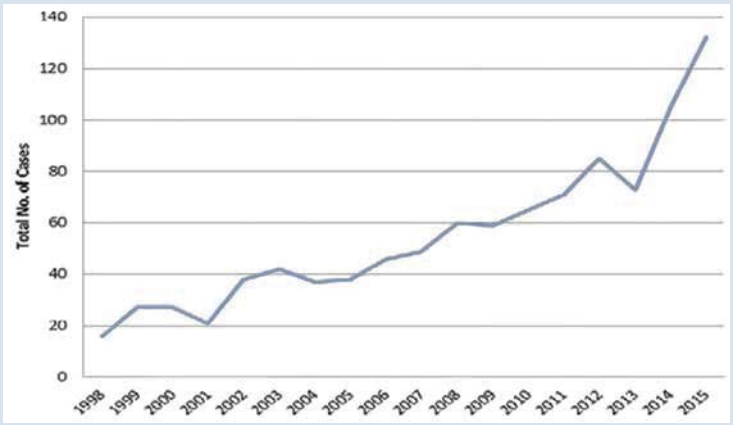
The use of euthanasia and assisted suicide in practice is far out of proportion to the situations that were originally used to justify the practice in these jurisdictions: namely, the small minority of cases where the symptoms of pain are unmanageable.

Moreover, the rapid growth in documented cases of euthanasia and assisted suicide probably understates the actual prevalence of the practice. There is a widespread failure of safeguards and procedures across jurisdictions, including low rates of reporting.

Greater awareness of access to euthanasia or assisted dying could possibly have driven a growth in the number of cases in



Netherlands: increase in euthanasia cases since 2008[17]
Compound annual growth rate: 13.1%



Oregon: increase in assisted suicide reports, 1998-2015[18]
Compound annual growth rate: 13.2%

the months and even years following introduction of each scheme. But high growth rates in total numbers have not abated in any jurisdiction, even where data exists for periods of almost two decades. There is no indication that growth rates are slowing in any jurisdiction, suggesting that sustained growth is due to factors other than community awareness.

An aging demographic is often put forward as a possible reason why the number of cases is rising – but is not a major factor driving the growth in the number of cases of euthanasia or assisted dying in any of the jurisdictions for which data is available. The total number of deaths over the period 2000-2010 grew at less than 1 per cent per annum in all relevant jurisdictions – and indeed it fell in the Netherlands.

There is an ethical difference between a decision to end or withdraw treatment by a health practitioner and the health practitioner actively taking part in ending someone's life. Even for those who believe that difference is not meaningful, the distinction between withdrawing treatment and undertaking a positive action is clearly defined.

But the situation is less clear for those who believe that euthanasia or assisted suicide can be ethical in some situations. Should it be available only for people with a terminal condition or also for those suffering from a condition that is "unbearable", albeit not terminal? Is physical pain necessary to trigger justifiable action or is psychological pain also sufficient? Is explicit consent required? If euthanasia or assisted suicide is justified only for people suffering from a terminal condition, what does "terminal" mean? Must death be expected within 3 months, 6 months, or a year? Should an age limit be placed on consent? And so on.

The reason why the "slippery slope" argument has credibility in this context is that, once euthanasia or assisted suicide is accepted for a limited subset of situations, there is very little by way of logical or philosophical argument to stop the expansion of categories. That expansion is precisely what is happening in Belgium and The Netherlands.[19,20]

A recent article by a former review committee member in the Netherlands, Theo Boer, notes a shift in the type of patients who seek assisted dying:

> beginning in 2007, the numbers of assisted dying cases started going up by 15 percent each year. In 2014 the number of cases stood at 5,306, nearly three times the 2002 figure.
>
> A shift has also taken place in the type of patients who seek assisted dying. Whereas in the first years the vast majority of patients—about 95 percent—were patients with a terminal disease who had their lives ended days or weeks before a natural death was expected, an increasing number of patients now seek assisted dying because of dementia, psychiatric illnesses, and accumulated age-related complaints.
>
> Terminal cancer now accounts for fewer than 75 percent of the cases. Many of the remaining 25 percent could have lived for months, years, or even decades. In some reported cases, the suffering largely consists of being old, lonely, or bereaved.[21]

Some advocates claim that legalisation of either euthanasia or assisted dying will bring practices such as euthanasia without consent into the open.

But studies such as that by Van der Heide in *The Lancet* found that ending of a patient's life without request occurred at the highest rates in Belgium and The Netherlands – where euthanasia and assisted dying are legal.[22]

Conclusion

Euthanasia and assisted suicide are a disproportionate response to suffering – causing far more social harm than good.

Legalising euthanasia and assisted suicide has been promoted as a way to bring what has been occurring in the shadows into the light. But instead, legalisation has simply pushed out the boundary of what is legal. It may have actually increased the amount of activity that occurs beyond the sight of regulators.

In countries with legalised euthanasia or assisted suicide, many vulnerable people are being placed in difficult situations where they have to make irreversible, complex choices under a great deal of pressure.

Evidence suggests that for such people, there is significant doubt that legal safeguards are working as intended. It is very unfortunate that some symptoms of pain cannot be totally managed – but the legalisation of euthanasia or assisted suicide is not the appropriate response.

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