EOLC Sub 445
Rec'd 20/10/2017

Submission

to the

Joint Select Committee on End of Life Choices

Dr Jeannine Purdy (Principal Research Officer)
WA Parliament
Harvest Terrace
West Perth, WA 6005
Email: eolcc@parliment.wa.gov.au

by

Rev Margaret Court AO, MBE
Victory Life Centre

1 Neil Street
Osborne Park WA
Telephone: 08 9212 7111

Website: www.victorylifecentre.com.au

20 October 2017

Dear Chairman

Re: Joint Select Committee on End of Life Choices

Thank you for the opportunity to lodge a submission on this very important issue.

I understand that the End of Life Choices is a debate that is raging throughout this country and the world. Yet I find myself aghast that the Western society has stooped to even consider legally permitting the robbing of life and may possibly micro mismanaged this issue of life and death.

To look at death which is the circle of life, we have to realize that life is gift, I believe a gift from God. The Bible states that mankind has been given dominion over the earth, but not dominion over each other. Mankind as an altruistic society serves the best interests of the individual and therefore all: Police, Army, Air force, National Security, medical professionals, SES, government bodies, rush to preserve life and yet we are discussing options on doing the opposite and robbing life from our most vulnerable and marginalised Australians.

Australia removed capital punishment decades ago; it was decided that Government and Judicial systems do not have the right to take life and yet the proposal of this committee is do that very thing, in opposition to conscience, duty of care and professional capacity of civil government and its department.

I think we have to ask ourselves: in our advance society do we continue our endeavour to preserve life and not legislative capital punishment to our weak, vulnerable and marginalized people – the ones in which the strong in conscience should protect at all measures?

Life is a miracle, to hold a newborn in our arms, we all marvel at life – we internally promise to protect, love and care for this baby. We as parents make this commitment and now our parents are in our arms asking us to love, care and protect them in their vulnerable state. How can we not do the same. Palliative care in this country is amazing; we should be reconsidering our effort, finances and expertise in advancement in this area.

My submission will address, through Dr Megan Best *(Euthanasia)* and Professor Margaret Somerville (*Unaddressed issues in the Australian Euthanasia Debate*), an overview of the issue worldwide and within Australian and is aimed at the Terms of Reference (a)

Terms of Reference

(a) assess the practices currently being utilised within the medical community to assist a person to exercise their preferences for the way they want to manage their end of life when experiencing chronic and/or terminal illnesses, including the role of palliative care;

In summary I echo Prof. Somerville words:

"*Legalizing euthanasia would be a seismic shift in Australia's foundational societal value of respect for human life. It is different-in-kind not just different-in-degree from medical interventions we currently regard as ethical and legal. It is not, as pro-euthanasia adherents argue, just another small step along a path we've already taken in respecting refusals of treatment even if that results in death and requiring fully adequate pain management to be offered to patients. Euthanasia rebrands killing as kindness, which is very dangerous.*

In deciding whether to legalize euthanasia we should keep in mind the axiom that "nowhere are human rights more threatened than when we act purporting to do only good", as that sole focus on doing good blinds us to the unavoidable risks and harms also present. "

Please allow me to introduce two excellence Australia woman, leaders in their field in both nationally and internationally that clearly and concisely relay major concerns in this area.

DR MEGAN BEST PhD, MAAE, BMed(Hons), AssocDegTh, GradDipQHR, ClinDipPall Med

Dr Megan Best graduated from medicine with the University Medal. After training in palliative care, she worked as a consultant for the NSW state and federal health departments, developing palliative care policy for several years before returning to clinical palliative care. She has maintained a life-long interest in developing evidence-based and ethical healthcare policy, contributing to many areas of legislation.

She has post-graduate qualifications in applied ethics in healthcare and teaches bioethics at tertiary level at several Sydney institutions. She is the author of two books exploring ethical issues at the beginning of life, as well as many journal articles. She is affiliated with Sydney Health Ethics (formerly VELiM) at the University of Sydney.

She was awarded her PhD at The University of Sydney for her thesis on the role of the doctor in the spiritual care of cancer patients. She is involved with developing curricula for spiritual care training of healthcare providers at both national and international levels. She is currently researching cancer genomics at Sydney University as a post-doctoral fellow for the Cancer Institute of NSW and at the University of Notre Dame Australia with the Institute of Ethics and Society.

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 if 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 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.

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 defendable 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 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.

© Dr Megan Best 2017

1. Kissane DW, Street A, Nitschke P. Seven deaths in Darwin: case studies under the Rights of the Terminally Ill Act, Northern Territory, Australia. The Lancet. 1998;352(9134):1097-102.
2. Good P, Ravenscroft P, Cavenagh J. Effects of opioids and sedatives on survival in an Australian inpatient palliative care population. Internal medicine journal. 2005;35(9):512-7.
3. Roy DJ, Rapin C-H. Regarding euthanasia. European Journal of Palliative Care.

1994;1(1):57-9.
4. Best M, Aldridge L, Butow P, Olver I, Webster F. Conceptual Analysis of Suffering in Cancer: a systematic review. Psychooncology. 2015;24(9):977-86.
5. Glare PA. The euthanasia controversy. Decision-making in extreme cases. The Medical journal of Australia. 1995;163(10):558.
6. Hudson PL, Kristjanson LJ, Ashby M, Kelly B, Schofield P, Hudson R, et al. Desire for hastened death in patients with advanced disease and the evidence base of clinical guidelines: a systematic review. Palliative Medicine. 2006;20(7):693-701.
7. Chochinov HM, Tataryn D, Clinch JJ, Dudgeon D. Will to live in the terminally ill. The Lancet. 1999;354(9181):816-9.
8. Johansen S, Hølen JC, Kaasa S, Kaasa S, Loge JH, Materstvedt LJ. Attitudes towards, and wishes for, euthanasia in advanced cancer patients at a palliative medicine unit. Palliative Medicine. 2005;19(6):454-60.
9. Kissane DW, Kelly BJ. Demoralisation, depression and desire for death: problems with the Dutch guidelines for euthanasia of the mentally ill*. Aust N Z J Psychiatry. 2000;34(2):325-33.
10. Chochinov HM, Hack T, Hassard T, Kristjanson LJ, McClement S, Harlos M. Understanding the Will to Live in Patients Nearing Death. Psychosomatics. 2005;46(1):7-10.
11. Chochinov HM, Kristjanson LJ, Hack TF, Hassard T, McClement S, Harlos M. Burden to others and the terminally ill. J Pain Symptom Manage. 2007;34:463-71.
12. Verhagen E, Sauer PJJ. The Groningen Protocol — Euthanasia in Severely Ill Newborns. New England Journal of Medicine. 2005;352(10):959-62.
13. Pieters J. Number of suicides in Netherlands at all time high.Netherland Times_http://www.nltimes.nl/2016/06/30/number-of-suicides-in-netherlands-at-all-timehigh/.Accessed 23/9/2016.
14. Onwuteaka-Philipsen BD, Brinkman-Stoppelenburg A, Penning C, de Jong-Krul GJF, van Delden JJM, van der Heide A. Trends in end-of-life practices before and after the enactment of the euthanasia law in the Netherlands from 1990 to 2010: a repeated crosssectional survey. The Lancet.380(9845):908-15.

Margaret Anne Ganley Somerville, AM, FRSC (born April 13, 1942) is Professor of Bioethics at University of Notre Dame Australia. She was previously Samuel Gale Professor of Law at McGill University.

Somerville was born in Adelaide, South Australia, and educated at Mercedes College (Springfield, South Australia). She received a A.u.A. (pharm.) from the University of Adelaide in 1963, a Bachelor of Law degree (Hons. I) and the University Medal from the University of Sydney in 1973, and a D.C.L. from McGill University in 1978

Among many honours and awards, in 1990, Somerville was made a Member of the Order of Australia "for service to the law and to bioethics". In 1991, she was made a Fellow of the Royal Society of Canada. In 2004 she was chosen by an international jury as the first recipient of UNESCO's Avicenna Prize for Ethics in Science.

She has received honorary degrees from University of Windsor (1992), Macquarie University (1993), St. Francis Xavier University (1996) and the University of Waterloo(2004). Her honorary degree awarded June 19, 2006, at Ryerson University in Toronto was controversial because of her objections to same sex marriage. She has since received honorary degrees from Mount Saint

Vincent University in Halifax, Nova Scotia (2009), St. Mark's College, Vancouver (2010) and the Royal Military College of Canada in Kingston, Ontario (2013).

In 2006, Somerville was nominated for membership in the Order of Canada by Carol Finlay, a professor at the Toronto School of Theology. Finlay says Somerville was turned down for the honour because she was "too controversial."

UNADDRESSED ISSUES IN

THE AUSTRALIAN EUTHANASIA DEBATE

Margaret Somerville

INTRODUCTION

I have researched and written on euthanasia and physician-assisted suicide for four decades while holding academic appointments in both the Faculty of Law and the Faculty of Medicine at McGill University in Montreal. In a series of decisions, which I believe future generations of Canadians will seriously regret, Canada has recently legalized these interventions. I have just left McGill and Montreal to take a position as Professor of Bioethics in the School of Medicine at The University of Notre Dame Australia in Sydney and find myself immediately involved in the same debate about legalizing euthanasia and doctor-assisted suicide as we had in Canada.

As part of my involvement in these activities, I have written seven short articles focused on different aspects of the debate. They are gathered together below.

The first warns that the impact of legalized euthanasia, especially its risks and harms to vulnerable people, cannot be properly judged in isolation from the total social milieu in which it would be practised and looks at its dangers in a "post-truth" society in which the abuse of elderly people is endemic.

The second examines the unsupportable claim of pro-euthanasia supporters that the evidence from jurisdictions which have legalized euthanasia and/or physician-assisted suicide shows that legalizing these interventions does not open up any "slippery slopes".

The third reports on the strategy of pro-euthanasia activists seeking to eliminate opposition to the legalization of euthanasia by labelling opposition as just a religious stance and arguing that religion and values based on religion have no place in the public square.

The fourth explores the importance of stories in forming our shared values and the impact of "good death" stories and "bad death" ones on the stances we take in the euthanasia debate. It relates a case where providing euthanasia 2

Margaret Somerville ©2017

was a “bad death” story, in contrast to the usual “good death” stories associated with its provision by pro-euthanasia advocates.

The fifth describes a recent experience I had as an invited panellist on a Q&A session on “Voluntary Assisted Dying”, held as part of Australian Medical Association Victoria Congress 2017. I experienced it as a serious suppression by pro-euthanasia advocates of my freedom of speech as a person who opposes the legalization of euthanasia. Legislators, in particular, need to be very aware of this danger in deciding for or against legalizing euthanasia.

The sixth looks at what we could learn of importance to the decision about legalizing euthanasia from the indigenous wisdom of looking back seven generations to consult human memory (history) and looking forward seven generations through imagination. If it is legalized and becomes the norm governing death, how will our great-great-grandchildren die? Will we have left to future generations a world in which no reasonable person would want to live?

And the seventh looks at the wider and deeper impacts of legalizing euthanasia beyond simply legalizing the intentional infliction of death and proposes that they include damage to important existential human experiences and our ability to find meaning in life.

Together these articles identify some of the unaddressed issues in the euthanasia debate. That they are unaddressed is not accidental. They are avoided by pro-euthanasia advocates because exploring them establishes the case against legalizing euthanasia.

The strongest case for legalizing euthanasia is made at the level of the individual, seriously suffering, terminally ill person, who is competent, gives informed consent and asks for euthanasia. The pro-euthanasia argument is that it is cruel to deny that request and kindness demands that it be honoured. The wider and deeper concerns and consequences that such honouring raises and results in, respectively, establish the case against legalizing euthanasia. I identify some of these concerns and consequences, which it is essential lawmakers take into account in deciding whether or not to legalize euthanasia.

Finally, just to be clear, as there is a great deal of confusion about the definition of euthanasia and doctor-assisted suicide, euthanasia is a doctor administering a substance to a person with the intention of killing the person, physician-assisted suicide is a doctor prescribing medication with the intention

that the person should use it to commit suicide. Justified withholding or withdrawal of life-support treatment or the provision of fully adequate necessary pain management, even if that could shorten life, are not euthanasia or assisted suicide.

***

i) POST-TRUTH, EUTHANASIA AND ELDER ABUSE: CONNECTING THE STORIES IN THE NEWS

Exploring the connections that can be made among three very recent stories in the news, which at first glance seem unrelated, can provide important insights and warnings. These stories are that "post-truth" is the Oxford English Dictionary's word of the year. That the Victorian Government will introduce an "assisted dying" bill in the second half of 2017 which, if passed, would legalize physician-assisted suicide and, in exceptional cases, euthanasia. And that the Australian Law Reform Commission has just released a discussion paper which documents elder abuse in Australia and seeks ways to prevent it.

a) "Post-truth"

Here's how Wikipedia describes "post-truth" in relation to politics: "Post-truth politics (also called post-factual politics) is a political culture in which debate is framed largely by appeals to emotion disconnected from the details of policy, and by the repeated assertion of talking points to which factual rebuttals are ignored. Post-truth differs from traditional contesting and falsifying of truth by rendering it [truth] of "secondary" importance." Or, one could add, of little or no importance at all.

In contemporary societies we increasingly use the prefix "post": post-industrial; post-modern; post-feminist; post-religious; and so on, and now post-truth. We know what we were, we know we are no longer that, but we don't yet know what we now are or are becoming.

Words are the tools of both truth and lies, so words matter. Nowhere is this truer than in the euthanasia debate.

4 Margaret Somerville ©2017

b) The euthanasia debate

Word changes can be subtle and nuanced. So, for instance, when, as has happened in promoting the legalization of euthanasia and physician-assisted suicide, more words are used to describe something that already had a name – euthanasia has become “physician assisted dying” and even the word death is dropped - we should know that we are being manipulated and something is being concealed. That something is the intentional infliction of death.

The strongest case for the legalization of euthanasia is made at the level of the suffering identified individual who wants to die when and how they choose. Pro-euthanasia activist Andrew Denton makes the case for legalizing euthanasia in this way in describing his father’s death. We feel compassion for his father and Mr. Denton, himself, for the suffering they both endured and our hearts rightly go out to them.

In a post-truth society feelings matter more than facts, the heart rules the head. So the facts about the larger impact of legalizing euthanasia – what it will mean for healthcare institutions, professions and professionals; how it will damage foundational societal values, such as respect for human life in general and the prohibition on intentionally killing another human being, except to save life; the impact in the future of normalizing euthanasia; and so on - are ignored or even denied.

Even hard factual evidence is rejected: In Canada the courts accepted the pro-euthanasia claim that in the Netherlands and Belgium, where euthanasia is legal, there was no “logical slippery slope” (the situations and persons eligible for euthanasia expand rapidly and very substantially once it is legalized) or “practical slippery slope” (euthanasia is carried out in breach of the law, especially on vulnerable people), when the evidence is clearly otherwise, as has been recognized by the Irish Supreme Court and most recently the Supreme Court of South Africa.

We can question whether the current “progressive values” stance of giving priority to respect for individual autonomy over upholding values, such as respect for life, needed to protect the common good, means that we have become a narcissistic society, one focussed just on individuals’ claims, and that the denial of facts which would cause us to reject those claims is a “narcissistic unawareness”.

5 Margaret Somerville ©2017

I hasten to add here that I am not denying the importance of feelings - they are one of the central ways of "human knowing" - but facts are, at the least, equally important, not least because good facts are essential for good ethics and good ethics is essential for good law.

And so to the third story where facts are needed and serious concerns raised about the abuse of one group of vulnerable people, namely, the elderly.

c) Elder abuse

Here's a 12th December 2016 ABC website headline: "*Elder abuse inquiry calls for power of attorney changes to stop children ripping parents off*".

The post continues: "A national register of enduring powers of attorney should be established to prevent greedy children from using the document as a "licence to steal" from their elderly parents, the Australian Law Reform Commission (ALRC) says", referring to an ALRC discussion paper which is part of its inquiry into elder abuse, which includes elderly persons being victims of financial fraud. The paper notes "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.

This is often described as "early inheritance syndrome".

"It's as if the current generation wants it now and somehow they justify that it's okay to take mum or dad's money right now," said Aged and Disability Advocacy Australia CEO, Geoff Rowe."

There are no concrete statistics on the prevalence of elder abuse in Australia, but a 2016 research report to the Australian Government Attorney-General's Department states that

"at the international level, the WHO (2015) recently reported that estimated prevalence rates of elder abuse in high- or middle-income countries ranged from 2% to 14% … and that the perpetrators are likely to be related to the victim… [and] one study suggests that neglect could be as high as 20% among women in the older age group (Australian Longitudinal Study on Women's Health

6 Margaret Somerville ©2017

[ALSWH], 2014). Older women are significantly more likely to be victims than older men, and most abuse is intergenerational (i.e., involving abuse of parents by adult children), with sons being perpetrators to a greater extent than daughters."

d) Combined effect

So consider in a "post-truth" society the combined effect in relation to elderly persons of "pressure and coercion", "early inheritance syndrome", abusers' self-justification of the abuse, 2% to 14% of elderly persons being victims of abuse, abusers being relatives, and women being more at risk than men, in the context of legalized euthanasia. At the very least, we should have second thoughts about whether legalization is a good idea.

***

ii) DENIAL OF "SCOPE CREEP" AND ABUSE IN EUTHANASIA: LOGICAL AND PRACTICAL SLIPPERY SLOPES

For a long time, it's puzzled me how proponents of the legalization of euthanasia can confidently claim, as they do, that in the Netherlands and Belgium, the two jurisdictions with the longest experience of legalized euthanasia, there have been no slippery slopes, when the evidence is clearly otherwise.

a) Definitions

The "logical slippery slope" occurs when the legalization of euthanasia for a very limited group of people in very limited circumstances is expanded to include more people in more situations. This has been described as "scope creep".

The "practical slippery slope" occurs when euthanasia is carried out in breach of the legal requirements as to either who may have access or the situations in which they must find themselves for euthanasia to be permissible.

b) Logical slippery slope

The logical slippery slope is inevitable once euthanasia is legalized and becomes common place, as we can see in what has happened in the Benelux 7

Margaret Somerville ©2017

countries. It's been rapidly expanded to more and more people in more and more situations. This is entirely foreseeable and to be expected. As we become familiar with interventions which we once regarded as unethical, our moral intuitions and ethical "yuck" factor responses become blunted and we move from rejection to neutrality, often even to approval of the action involved.

Legalizing euthanasia means that the rule that we must not intentionally kill another human being – this line in the sand which we must not cross, this most ancient ethical and legal barrier – is breached, indeed annihilated, and beyond it there is no other obvious stopping line which we must not violate, perhaps not even that euthanasia is only acceptable with the consent of the person on whom death is inflicted. People with Alzheimer's disease and other dementias have been euthanized in the Netherlands and Belgium.

Anti-euthanasia adherents believe that the prohibition on intentional killing of another human being is a line we must not cross, not only, because intentional killing is inherently wrong, but also, because, as British moral philosopher Dame Mary Warnock has put it, "you cannot successfully block a slippery slope except by a fixed and invariable obstacle", in the case of euthanasia, the rule that we must not intentionally kill.

There could also be a further explanation for the denial of a logical slippery slope by pro-euthanasia advocates, such as Oxford University bioethicist Professor Julian Savulesco and Andrew Denton in his address to the National Press Club, screened on ABC TV and iView, which is less obvious at first glance. This is that no potential slippery slope exists.

The basis for the pro-euthanasia case is that we must have respect for an individual's autonomy – their right to self-determination - including with regard to a decision that they prefer death to continued life and want help in terminating their life. Once that rationale is accepted and applied in its fullest sense, it's difficult to justify restrictions on access to euthanasia. Consequently, the diminishment or repeal of existing restrictions is not recognized as a slippery slope, rather, it's seen simply as more fully implementing respect for individual autonomy and the right to self-determination - the rationale used to justify euthanasia in the first place.

Consequently, it should not be surprising that the Dutch are now considering a special form of access to intentionally inflicted death for those who believe they have a "completed life", which they do not want to call or

8 Margaret Somerville ©2017

treat as euthanasia, although it involves the same type of death-inflicting intervention. The movement to legalize such an intervention started with a petition to the Dutch Parliament that those who were “over seventy and tired of life” should be able to have assistance in terminating their lives. The age requirement can be questioned as being inconsistent with the right to self-determination rationale for allowing the intentional infliction of death and it’s been reported that debate has begun in the Dutch media on eliminating it.

c) Practical slippery slope

Pro-euthanasia advocates’ denial of a practical slippery slope – administration of euthanasia other than in compliance with the law – despite clear evidence to the contrary, might also be able to be explained on a related basis. If one believes there should be more or less open access to euthanasia, then legal requirements are annoying impediments and their breach is a trivial matter and as the old saying goes “de minimis non curat lex” – the law does not concern itself with trifles.

Another element in this denial might be acceptance of the “non-deprivation justification” of euthanasia, which was considered approvingly by Canadian courts in ruling that an absolute prohibition of euthanasia was unconstitutional. The rationale of this argument is that a person’s quality of life can be so bad, that the bad in continuing to live outweighs any good experienced in doing so, such that nothing good is lost if one is euthanized – there is no deprivation of anything worthwhile or valuable - indeed death can be seen as a benefit.

A breach of the law which is seen as trivial and as conferring a benefit is unlikely to be characterized as an abuse by those supporting euthanasia and so, like the logical slippery slope, the practical slippery slope is defined out of existence.

***

iii) EVICTING RELIGIOUS VOICES FROM THE PUBLIC SQUARE IS ANTIDEMOCRATIC AND DISCRIMINATORY

a) “Label as religious and dismiss” strategy

The Australian reports “Denton tells church to get out of euthanasia debate” (August 11, 2016) and the ABC website that “Andrew Denton has

9 Margaret Somerville ©2017

lashed out at a 'subterranean Catholic force' of politicians and businessmen who he claims continue to thwart attempts to allow legally assisted voluntary euthanasia in Australia."

This is the "label as religious – in particular, Roman Catholic - and dismiss" strategy of pro-euthanasia advocates. It's applied to both clergy and members of the public with religious beliefs. The strategy is founded on the argument that religious beliefs are unacceptable as an informing principle for values decisions other than purely personal ones, especially those decisions relevant to public and social policy, and, consequently, religious people's voices should be excluded from the public square.

It's a strategy used to avoid addressing the arguments or views of people with religious beliefs, whether or not their arguments and views are religiously based: They *and their arguments* are dismissed simply on the basis of having a religious affiliation. The assumption underlying this strategy and purportedly justifying it is that people who have religious beliefs are puppets of their Church - unthinking, uncritical automatons.

People like Mr. Denton, who use this strategy, overlook that everyone has a belief system. For example, secularism and atheism are belief systems, yet their adherents are not automatically dismissed for being such and should not be, because in a democratic society everyone has a right to a voice in the public square. To silence people because they are religious is anti-democratic and discrimination, just as silencing atheists and secularists would be.

If Mr. Denton has good arguments against his Catholic opponents' positions he should present them and show why these Catholics' arguments should not prevail, instead of trying to suppress them. Indeed, his efforts to do the latter raises the issue of whether he believes his arguments will fail if they are competently challenged.

b) Emotions and moral intuitions matter

The euthanasia debate involves ethical decision-making, therefore, not only reason, but also other human ways of knowing, such as "examined emotions" and intuition, especially moral intuition, play an important role. A wise axiom in applied ethics is that "we ignore our feelings at our ethical peril." That is not to say we should act just on the basis of our emotional reactions, but that we must carefully examine these reactions and take them into account in ethical decision making.

10 Margaret Somerville ©2017

We must react with compassion and care for people who are suffering from horrible illnesses, but our reaction should be to kill the pain and suffering, not the person with the pain and suffering.

Humans have an innate reluctance to killing another human being and rightly recoil from doing so. Indeed, in the past, soldiers have been psychologically deprogrammed in order to be able to kill an enemy soldier at close quarters. So might we need to be more concerned about the ethics of doctors willing to inflict death, than the ethics of those who refuse to do so for reasons of conscience or religious belief?

A case in point has arisen in Canada where euthanasia has recently become legal. Pro-euthanasia advocates are trying to force doctors with conscientious or religious objections to euthanasia to participate in it, which is clearly unethical and wrong. We should keep in mind that a doctor's good conscience is a patient's last protection.

c) Words matter

Our choice of language is important and influential with regard to emotional and intuitive responses. For instance, Mr. Denton's use of the word "subterranean" in describing "a Catholic force" brings to mind secret, dark, nefarious forces and conspiratorial activity.

Pro-euthanasia advocates such as Mr. Denton speak in the neutral terminology of "assisted death" (we all want medical assistance when we are dying). They assiduously avoid the language of doctors inflicting death on their patients or, even more graphically, being allowed to kill them, as these latter descriptions rightly raise many people's moral and ethical concerns about this practice.

Very recently, Mr. Denton announced the launch of a pro-euthanasia lobby group called "Go Gentle Australia". It sounds like a catchline in an advertisement for Kleenex or toilet paper.

d) Seeking meaning in suffering

Mr. Denton had a traumatic experience with his father's death and is seeking to have some good – his perception of what is good - come out of that. He wants to make sure that others will benefit from the suffering his father endured by trying to ensure that they do not experience the same suffering. In

11 Margaret Somerville ©2017

short, he wants to give his father's suffering meaning. Seeking meaning, especially in suffering, is innate to being human.

However, euthanasia will seriously harm our capacity to find meaning in the face of death, not promote it. It converts the mystery of death to the problem of death and offers a quick-fix technological solution to the problem, a lethal injection.

In contrast, making available fully adequate access to high quality palliative care for every Australian who needs it will help people to find meaning in the last days of life until death occurs naturally.

I note here that seeking good for others out of a traumatic medical event, such as Mr. Denton and his father experienced, is a very common reaction of people who themselves or their child, spouse or parent have been the victim of medical malpractice. Failure to take all reasonable steps to relieve the pain and suffering, especially of terminally ill people, is medical malpractice and, as is recognized in the Declaration of Montreal 2010, a breach of fundamental human rights.

I also note that the case Mr. Denton describes in his submission to The New Zealand Parliamentary Health Select Committee of the dying woman, who was in excruciating pain but refused pain management until a certain pre-determined time represents a gross violation of ethical medical practice, unprofessional conduct, medical malpractice (actionable negligence) and possibly criminal negligence. (See the Declaration of Montreal on pain management, which has been affirmed by the World Health Organization and the World Medical Association, which represents 9 million doctors worldwide.) This patient needed competent palliative care, not a lethal injection.

e) Identifying wider and deeper issues

The strongest case for legalizing doctor-assisted suicide and euthanasia is the one Mr. Denton makes, that is, the relief of the suffering of individual competent adults who want and consent to this. But, in deciding as a society whether to legalize doctor-assisted suicide and euthanasia, we must look beyond what an individual might want and consider far wider issues.

Importantly, these include:

12 Margaret Somerville ©2017

- the impact of euthanasia on fragile or vulnerable people – those who are old or live with disabilities, or even just perceive themselves as a burden on their families;
- the impact on suicide prevention of the normalization of suicide as an acceptable response to suffering; and
- what it means for society and our shared values to move from caring for those unable to care for themselves to killing them.

What would be the impact on important values, such as respect for human life, in general, in society? Respect for life must be upheld at both the individual and the general societal level.

If fully adequate palliative care is not available, what would it mean that we are saying "we will not care for you but we will kill you"? Religion used to carry the value of respect for life for society as a whole, but in a secular society, such as Australia, the institutions of law and medicine carry this value. How would their capacity to do this be affected by society changing the law to allow the infliction of death and permitting doctors to do that?

f) Outcome in practice of legalizing euthanasia

Finally, what would the practical reality be if euthanasia were legalized in Australia? Most advocates of euthanasia propose there's no danger in legalizing it because it will be rarely used and only in extreme circumstances. Mr. Denton is reported as saying that "less than 4 percent of deaths in The Netherlands were as a result of assisted death", seemingly, and quite astonishingly, as demonstrating that this is a rare outcome. But if the same rate applied in Australia as in The Netherlands, using the lower more accurate figure of 3.6 percent, there would be around 5000 euthanasia deaths each year. Are we prepared to allow that? Can we live with it?

***

iv) THE IMPORTANCE OF STORIES IN THE EUTHANASIA DEBATE

a) Making the pro- and anti-euthanasia cases

13 Margaret Somerville ©2017

The pro-euthanasia case is compact and quick and easy to make: It focuses on a terminally ill, seriously suffering, competent adult who gives informed consent to euthanasia and bases its claims to prevail on the obligation to respect that person's right to autonomy, self-determination and dignity.

The case against euthanasia is more complex and time-consuming to establish. It requires placing euthanasia in a much wider context that takes into account, among many other considerations, what its impact would be, not only in the present, but also in the future, and what protection of both vulnerable people and society demands.

b) Clash of values

Euthanasia involves a clash of two important values: respect for individual autonomy and respect for life. Pro euthanasia advocates give priority to autonomy; anti-euthanasia proponents to respect for life.

Respect for life is not just a religious value as pro-euthanasia advocates argue. All societies in which reasonable people would want to live must uphold respect for life and at two levels: Respect for every individual human life and respect for life in society in general. Even if legalizing euthanasia were viewed as not contravening the former, it seriously harms the latter.

Both the pro- and anti- euthanasia sides in the euthanasia debate are trying to persuade the public to affirm their stance. So how are they presenting their cases to the public?

c) Shared "death stories"

We form and support or reject the shared values on which we found our society, in part, by creating stories that we tell each other and buy into, in order to create the glue that binds us together as a community.

The pro-euthanasia case relies on "bad natural death" stories - stories of the extreme suffering of some terminally ill people who die a natural death - and characterizes and promotes euthanasia as an essential-to-provide kindness and its prohibition as cruelty.

Anti-euthanasia advocates often counter these stories with "good natural death" ones of people dying naturally and peacefully, in the presence of those they love, feeling that they have had a completed life. ("Good death" stories do not assume that death can be good, but rather that the process of dying a natural death can be "good" or "bad" and that we can to a large extent

influence which of these it is by the physical, psychological and spiritual care that we provide to the dying person.)

But there are also some "bad euthanasia death" stories, which support arguments against legalizing euthanasia. One, by journalist Guilia Crouch, was posted on the Mailonline on 28th January 2017. (http://www.dailymail.co.uk/news/article-4166098/Female-Dutch-doctor-drugged-patient-s-coffee.html-) It gives an account of the following facts:

Last month, a Dutch Regional Euthanasia Review Committee reported on a case brought before it: The woman patient had dementia. A woman doctor put a sedative in her coffee as a prelude to euthanizing her. The doctor said she didn't tell her of the sedative or her plans for euthanasia, "because she did not want to cause her [patient] extra distress". In deciding to euthanize her patient, the doctor was relying on a phrase in the patient's declaration in her will that she could consider euthanasia "when I myself find it the right time".

While being injected with the lethal drug, the woman woke up. She struggled and the only way the doctor could continue with the injection was by asking the woman's family to help to restrain her, while she continued with the injection. The woman's case notes recorded that she had said several times during the previous days, "I don't want to die".

The review committee concluded that the doctor "had crossed the line" by secretly giving the sedative and not stopping the injection when the woman resisted and had too broadly interpreted the woman's declaration, but that the doctor had acted in "good faith" and should not be punished.

However, the chair of the review committee wants the case brought to court to create a precedent to enable other doctors to lethally inject people with dementia, without fear of legal repercussions.

d) So what can we learn from this story?

Even if we believe that euthanasia is not inherently wrong, its risks and harms to vulnerable people – those with disabilities, the elderly and the fragile - outweigh any benefits.

I have written previously, about the Australian Law Reform Commission's research on elder abuse - between 4 and 14 percent of old people are abused most often by a close relative. It's hard to imagine a more extreme form of

15 Margaret Somerville ©2017

abuse than helping a doctor to euthanize an elderly relative by restraining the "loved one" who doesn't want to die.

The Commission was concerned in particular about "early inheritance syndrome", where a person, usually a child of the old person, obtains a power of attorney and uses the financial assets of their parent for themselves.

Many people worry about the cost of residential care for their elderly relatives and heirs see "their" inheritance, to which they feel entitled, dissipating. Many old people say they would rather be dead than go into a nursing home. Imagine adding euthanasia to this situation – it would certainly be a lethal cocktail.

e) Moral hazards

Euthanasia is, what is called in ethics, a moral hazard – that is, it opens up possibilities of breaches of ethics, such as I've just described.

A response might be that the moral hazard risk of euthanasia can be avoided if only assisted suicide is legalized. But it too is a moral hazard. Research shows that high on the list of reasons people want to die is that they feel that they are a burden on loved ones and there is an ever present danger of coercion.

There is also a broader moral hazard from assisted suicide: the general suicide rate has increased in jurisdictions that have legalized assisted suicide. (http://sma.org/southern-medical-journal/article/how-does-legalization-of-physician-assisted-suicide-affect-rates-of-suicide/; http://alexschadenberg.blogspot.ca/2016/03/rushing-toward-death-euthanasia-in.html) This is not surprising: state sanctioned assisted suicide endorses suicide as an appropriate response to suffering and suicide is contagious. Suicide is also the leading cause of death in young adults. This is a serious and major public health concern, which legalizing assisted suicide would only magnify.

How could this Dutch doctor have done what she did? That same question has been pondered over and over again in relation to the Nazi doctors.

It's a result of a process of incremental desensitization of the doctor to what is involved: namely, killing her patient.

This desensitization results from multiple factors: Placing the "white coat" of medicine on euthanasia carries with it messages of the ethical validity of

euthanasia and its kindness. The language used to describe euthanasia is massaged and euphemized. The doctor is blinded by a conviction that this is best for the patient and she's only doing good for her. The doctor has no conscious recognition that this is not medical treatment and that she is acting contrary to medicine's healing mandate and beyond the proper goals of medicine.

The doctor's equanimity may, however, be only on the surface. At a deeper level of the psyche, carrying out euthanasia may have harmful impact on healthcare professionals. Doctors in the Netherlands and Canada are opting out because they are suffering mental trauma, including PTSD, from providing it. Some Canadian doctors who placed their names on a list of doctors willing to provide euthanasia withdrew their names after undertaking their first case saying it was too traumatic for them and they never wanted to do it again. (http://alexschadenberg.blogspot.com.au/2017/02/canadian-doctors-are-struggling-with.html?utm_source=EPC+Contacts&utm_campaign=b51a17a348-EMAIL_CAMPAIGN_2017_02_15&utm_medium=email&utm_term=0_d113c154ac-b51a17a348-157716225)

This too is not surprising: Doctors are trained to heal and save life wherever possible, not to intentionally take life. And all mentally healthy human beings have a powerful instinct against killing another human being.

We must never ignore the heart wrenching pleas of both those who are suffering and those who love them and want the loved one's suffering ended. But we must kill the pain and suffering, not the person with the pain and suffering.

***

v) SHUTTING UP BY SHOUTING DOWN: THE SUPRESSION OF ANTI-EUTHANASIA STORIES: RESPECTING BOTH SIDES FREEDOM OF SPEECH IN THE EUTHANASIA DEBATE

a) The context

Very recently, I was a participant in a Q&A panel on "Voluntary Assisted Dying" at the Australian Medical Association Victoria Congress 2017. I was

17 Margaret Somerville ©2017

pleased to have been invited and hopeful that there would be a balanced discussion, but also somewhat concerned that might not be realized in practice, given the membership of the panel.

The panel participants included the well-known advocate of the legalization of doctor-assisted suicide Andrew Denton and the leader of the Greens, Senator Richard Di Natale, who also supports its legalization in certain circumstances.

Unfortunately, my concerns materialized.

b) The events

First, my participation in the discussion was limited in several ways. Shortly before the event, the chair telephoned to tell me that the question of whether or not legalizing doctor assisted suicide or euthanasia was a good or bad idea, ethical or unethical, was not open for discussion.

She explained that the only topic to be discussed was the conditions which should apply for access to assisted suicide and how it should be regulated. In short, the panel was based on an assumption that legalizing assisted suicide was inevitable in Victoria, even though legislation has not yet been tabled in the Victorian Parliament, let alone debated or enacted. This assumption is a pro-assisted suicide/euthanasia strategy as it leads people to believe there is no point in discussing views opposing legalization.

Legislative bodies only regulate conduct that they and the community consider to be ethical under certain conditions and they regulate to set out those conditions. We prohibit conduct we believe to be inherently unethical, as those who oppose euthanasia believe it to be. Consequently, discussing regulation affirms the ethical acceptability of assisted suicide and euthanasia.

On more than one occasion, I was told by the chair that I had been invited as a lawyer and not an ethicist, despite the fact that the latter has been my main professional role for forty years. Given this proviso, it was not unexpected that the questions addressed to me from the chair were purely legal ones; for instance, I was asked to define mental capacity and dignity. This gave me speaking time and an appearance of fair time allocation among panellists, without my necessarily being able to address the anti-assisted

18 Margaret Somerville ©2017

suicide/euthanasia arguments I wanted to propose, but I took the opportunity to present briefly some of them.

A theme developed by the panellists who agreed with legalizing assisted suicide was that being absolute on the issue of its legalization is "not helpful" and that the voices in the public square debate should be those of reasonable people who were not absolutists. This, in fact, amounts to another pro-euthanasia strategy, because if one is not against the legalization of assisted suicide or euthanasia, one is necessarily for it in some form. While some people might be uncertain where they stand, and many people say they are, there is no entirely neutral position.

At the beginning of the event, the chair told the audience that they should text questions to her and that she would collate and present them; those who did not have an iPhone were told they should raise their hand and ask the question in person. She added that if the questioner spoke for too long or was presenting commentary or policy, rather than a question, the audience could shout "No, no, no!" and she would cut off the person.

It seems reasonable to assume this invitation was offered only in relation to an audience member asking a question. But when I prefaced an intervention by saying that I wanted to describe a case of euthanasia that showed its risks and harms, the chair interjected and said "No stories please", and a substantial percentage of the audience immediately joined in to shut me down, shouting, "No, no, no, no stories".

In forty years of giving speeches on average around twenty five to thirty times a year, I have never encountered such an incident. Moreover, bear in mind that I was an invited guest speaker sought out by the AMA to be a Q&A panellist at the congress and the audience were all, or almost all, medical doctors.

This behaviour does not fulfil the requirements of respectful discussion. Indeed, it is designed to stifle, rather than facilitate, debate on an important social and medical issue, and I felt intimidated.

A positive aspect of the panel was that Andrew Denton - one of the very few people present who was not a medical doctor - did behave respectfully with regard to my anti-euthanasia arguments and towards me. And a positive and important message, delivered by the gerontologist and psychiatrist on the panel, was that we shouldn't even be talking of legalizing euthanasia until we

19 Margaret Somerville ©2017

have fully adequate palliative care available to all who need and want it, which is far from the case at present in Australia.

In summary, I experienced this panel as involving silencing and intimidation and a failure to respect freedom of speech.

c) Self-censorship

Many people with traditional or conservative values, especially young people, when they encounter such experiences respond by self-censoring. They tell me, privately, that they share some of the values I present, but would never say so publicly for fear of being ridiculed or shamed or, even, not being employed or promoted. The same is true of many conservative politicians who fear losing votes.

Indeed, I had initially decided not to publish this article for fear that I and the case against doctor-assisted suicide and euthanasia would be discredited by being characterized as extreme and summarily dismissed. But then I realized that I, too, was falling prey to self-censorship.

We should also always keep in mind in the euthanasia debate that whether we are pro- or anti- legalizing doctor-assisted suicide and euthanasia, we have a common goal of relieving suffering. Where we disagree is the limits on the means we may use to do this. As I've written elsewhere, I believe we should kill the pain and suffering, not the person with the pain and suffering.

d) The wider consequences

The vignette that I describe has wide moral and ethical implications in relation to the quality and character of public debate, which is essential to a healthy democracy and maintaining a society in which reasonable people would want to live.

Perhaps one of the most disturbing aspects of this event is that it was an Australian Medical Association Victoria congress and, as I've noted already, almost everyone present, whether as speakers or in the audience, was a medical doctor. In secular, democratic, pluralist, multi-cultural societies like Australia, medicine is a major values-creating and values-carrying institution for society as a whole, because it is one of the few institutions to which we all personally relate. That means it must be open to taking into account the full range of people's commitments and values systems.

20 Margaret Somerville ©2017

We need to ask whether, in the organization and conduct of this doctor assisted suicide-euthanasia panel, the AMA Victoria lived up to its responsibilities in this regard.

***

vi) LESSONS FROM INDIGENOUS WISDOM IN THE EUTHANASIA DEBATE

a) Looking to the past and the future in deciding about legalizing euthanasia

Some time ago, I was a member of an ethics committee set up as part of the Nuclear Waste Management Organization established by the Canadian Government to advise it on how it should deal with the complex issue of the disposal of nuclear waste.

At the first meeting of the committee, the chairperson asked us each to introduce ourselves and to make some brief remarks relevant to the disposal issue.

George Erasmus, who was the national chief of the Assembly of First Nations from 1985 to 1991, was a committee member. When it came to his turn, after a long moment of silence, George said softly, “Well if it had been up to us, we would never have been in this position, because we would never have allowed the technology that results in nuclear waste. We would have looked back seven generations for lessons from our ancestors and looked forward seven generations to its risks and harms to future generations and decided against its use.”

George’s words came to mind as wise advice for those of us engaging in the legalization of euthanasia debate currently raging in Australia. They struck me as especially *a propos* in light of the fact that Aboriginal and Torres Strait Island and First Nations communities in Australia and Canada, respectively, are, in my anecdotal experience, uniformly and adamantly opposed to euthanasia. What might these indigenous communities be perceiving that pro-euthanasia advocates are not?

Looking back seven generations is to consult history or, as John Ralston Saul evocatively calls it, “human memory”.

21 Margaret Somerville ©2017

Since the time of Hippocrates 2,400 years ago, medicine has a history of the absolute prohibition of physicians intentionally killing their patients. Why now do some people want to abandon this foundational value guiding the practice of medicine?

We have always been faced with death and suffering and have never seen euthanasia as ethically acceptable medical treatment or, indeed, as medical treatment. Why then, when there is so much more we can do to relieve suffering, might our society suddenly think it is a good idea to allow doctors to inflict death? The contributing factors are multiple and complex, but at base the cause is a sole focus on upholding the individual's absolute right to autonomy and "choice", to the exclusion of other balancing considerations that should be taken into account.

b) The need to protect individuals AND the common good

These other considerations include what approach is needed to protect the common good, that is, the well-being of the community as a whole, not just the wishes and claims of an individual person, important as these are. The cultures of indigenous peoples are more cognisant of this need to protect the community and attuned to it, which could be one reason they reject euthanasia.

Pro-euthanasia advocates adamantly reject that the history of the Nazi horrors has anything to teach us and scorn anyone who dares to suggest that, when judiciously examined, it might provide insights and warnings. It's true that we will not see a Holocaust resulting from the legalization of euthanasia, but some of the origins of the Holocaust - in German doctors' involvement in small, allegedly well-motivated and compassionate medical acts and the justifications used to validate these acts - carry serious warnings that deserve attention in the current debate.

In using their imaginations to look forward seven generations in order to be warned of future harms and risks to their descendants, indigenous communities are again seeking to protect not only individuals, but also the community. How a person dies, when death is caused by euthanasia, affects not only that person, but also unavoidably affects others and the community, and not just in the present but also in the future.

To summarize, the strongest case for legalizing euthanasia is based in radical individualism and "presentism". It focuses on a suffering, competent

22 Margaret Somerville ©2017

adult individual who asks for and gives informed consent to euthanasia to the exclusion of the impact on the community of allowing euthanasia, and ignores what we could learn from considering it in the context of both the past and the future.

c) Questions we must address

So in deciding about legalizing euthanasia we should learn an important lesson from indigenous wisdom and ask ourselves questions which include: How do we *not want* our great-great-grandchildren to die? What must we *not do* now if we are to leave to future generations a society in which reasonable people would want to live? Would an Australian society in which euthanasia had become a norm be such a society?

In thinking about that last question, further realities can be brought to light. If, as Andrew Denton claims, Australia will have the same rate of deaths by euthanasia as the Netherlands and Belgium, around 4 percent of all deaths, that will result in around 6000 euthanasia deaths annually, which would make euthanasia the sixth leading cause of death in Australia. It would fall between respiratory diseases and diabetes on the Australian Bureau of Statistics "Causes of Death 2015" list, and there would be 25 percent more deaths by euthanasia than from diabetes, five times the number of deaths from road accidents (1200 per annum) and twice the number of deaths from suicide (3000 per annum). Could Australians accept that?

The population of the Victorian town of Lakes Entrance is just under 6000. Would they be comfortable with wiping out with euthanasia each year the same number of people who presently live in that town?

***

vii) THE FLIGHT FROM MYSTERY: CHOICE, CONTROL AND FINDING MEANING AT THE END OF LIFE: THE CHALLENGE OF EUTHANASIA

a) "Choice, change and control"

People who espouse "progressive values", who include those advocating for the legalization of euthanasia, adopt a mantra of "choice, change and control".

23 Margaret Somerville ©2017

Choice maximizes respect for individual autonomy which is the preeminent value of "progressivists". Choice also allows change to be implemented and "progressivists", often naïvely, simply assume that change is always for the better. And power to change can give one a power to control or at least an illusion that one is in control.

Why only an illusion? There are some things that we cannot control, or indeed change, no matter how much we might like to be able to do so. Death is one of them.

It's an innate human characteristic to search for meaning and we do that whether or not we are religious. The questions the vast majority of us ask, "Who am I?" "Why am I here?", manifest and articulate our search for meaning. Many of us recognize that there is a mystery at the centre of our responses to those questions, which are asked most powerfully in seeking meaning in relation to death. Consequently, death involves a mystery which we must accommodate. We can do that in various ways.

Euthanasia seeks to take control over death. It does so, as I've noted previously, by converting the mystery of death to the problem of death and offering a technological solution to that problem, namely a lethal injection. In doing so, it destroys the mystery of death and, thereby, the possibility of finding meaning in the presence of death.

I want to make clear that I am not promoting religion here, although that is one way, and was until the post-modern era the most common way, to find meaning, in particular in death. Rather, I am proposing that all of us need to be able to find meaning, if we are not to become nihilists and lead a life of despair. Today, many people find meaning in life by devoting themselves to a worthy cause that benefits others, including future generations, but that doesn't help them to find meaning in death.

What I am proposing is that one of the serious harms of legalizing euthanasia is the intangible one of serious damage to our capacity to find meaning in death, which might be a requirement for finding meaning in life, in general. This might be caused, at least in part, by euthanasia's impact of trivializing death.

24 Margaret Somerville ©2017

b) The importance of shared stories, intimacy and leaving a legacy

We hear many stories of “bad deaths” told in support of legalizing euthanasia. Our hearts rightly go out to the people involved and we recognize that their motives of relief of suffering are good. But if we do not want to set in motion a much wider range of harms that legalizing euthanasia unavoidably causes, I propose that we must kill the pain and suffering, not the person with the pain and suffering. This makes it imperative that fully adequate palliative care, including pain management, be readily available to all who need it.

We should also balance the stories of “bad deaths” with those of “good deaths” – or perhaps it’s better phrased as deaths from which otherwise unavailable “goods” flow, not only to the dying person, but also, to many others. These include conversations that would never have taken place, reconciliations with family and long lost friends, and joys such as holding a first grandchild. French psychoanalyst Marie de Hennezel, who has cared for many dying people including President Francois Mitterand, describes this time and its possibilities as “intimate death”.

When we are dying, the vast majority of us also want to be remembered, to leave a legacy of our presence on this planet, and as Canadian psychiatrist Dr. Harvey Max Chochinov and his co-researchers have shown, we can help people to do this through a structured psychotherapeutic intervention which they call “dignity therapy”. This is an alternative to seeing euthanasia as necessary to respect a dying person’s dignity, a frequent justification of legalizing euthanasia.

c) Managing terror of death

Social psychologists propose that not just individuals, but also societies have a psyche and that both can experience terror. When we have a strong free-floating fear of something, for example, death, we seek to take control of it to reduce our fear and anxiety. The social psychologists speak of responding with “terror management devices” or “terror reduction mechanisms”. I believe euthanasia can be seen as such a device or mechanism for managing the fear of death. We can’t avoid death, but euthanasia allows those who seek it to get death before it gets them.

As individuals and a society we hide death away by euphemising the word. It is almost “politically unacceptable” to use “death”, “died” or “dead” in

25 Margaret Somerville ©2017

relation to a person's "passing". We hide from our fears, which hinders our own preparation for death. We could also see euthanasia as limiting the capacity of a dying person to help to prepare others for a "good death" by showing them what used to be called "ars moriendi" (t*he art of dying*). We have lost "death literacy".

d) Need for a deeper and broader societal conversation

Our conversation about whether it's a good or bad idea to legalize euthanasia needs to be much broader and deeper than it is at present. It's not sufficient just to focus on an individual suffering person who wants death inflicted, much as we must have the most sincere compassion for them and ensure that everything possible, other than killing them, is done to relieve their suffering.

Euthanasia raises profound issues about how we find meaning in life; its impact on law and medicine, the two institutions in a secular society which carry the value of respect for life for society as a whole; and its impact on one of our foundational values as a society, namely, that we must never intentionally kill another human being, except to save human life. Such considerations and many more must be taken into account in our decision making about legalizing euthanasia, if we are to act wisely and ethically. At present, the debate is very superficial and narrow and reduces one of the most solemn moments of life to a mere contractual undertaking.

CONCLUSION

Legalizing euthanasia would be a seismic shift in Australia's foundational societal value of respect for human life. It is different-in-kind not just different-in-degree from medical interventions we currently regard as ethical and legal. It is not, as pro-euthanasia adherents argue, just another small step along a path we've already taken in respecting refusals of treatment even if that results in death and requiring fully adequate pain management to be offered to patients. Euthanasia rebrands killing as kindness, which is very dangerous.

In deciding whether to legalize euthanasia we should keep in mind the axiom that "nowhere are human rights more threatened than when we act purporting to do only good", as that sole focus on doing good blinds us to the unavoidable risks and harms also present.

26 Margaret Somerville ©2017

Margaret Somerville

Professor of Bioethics

The University of Notre Dame Australia

School of Medicine (Sydney Campus)

13th March 2017