

To the Chairperson and Members of the Standing Committee on Legal and Social Issues Inquiry into End of Life Choices

Mr Chairman, Ladies and Gentlemen

I wish to suggest a new approach to end of life policy which would allow citizens of Victoria to make informed decisions regarding their own end of life choices, and give us all the personal agency and autonomy we do not now possess.

I wish to assist this Committee to break the needless nexus between the right of a person to choose her own death, and the endless, fruitless, community discussion about Physician Assisted Death, which has infiltrated and subverted the Voluntary Euthanasia discussion.

The simplest and fairest way to allow what is a fundamentally individual choice about end of life is to make that decision, and the act, truly personal by allowing citizens at age 60 or over to ask their General Practitioner for a prescription for Nembutal. Then, at a time of their choosing, citizens could have that prescription filled at a pharmacy in the normal way. In order to ensure that no fraud or mistaken identity occurs, those getting the prescription would be required to provide a high level of personal identification, as they are now required to do when purchasing pseudoephedrine in Victoria. Then if and indeed when, the prescription is ever filled, people may choose to take the drug and end their lives. Provision for extensions to the law could be

made for the terminally ill of all ages, even those unable to respond due to dementia or unconsciousness if they have recent, or recently re-ratified, Advanced Care Directives expressing their wishes.

This system would have many benefits, the most important of which is to put decisions about end of life directly and only in the hands of the person concerned. This system would give agency and autonomy to Victorian citizens. These are the key issues today in all aspects of medical practice and patient care *except end of life choices*.

These are also key issues in legal considerations of medical treatment. My proposed model may help to protect the Victorian government, agencies and hospitals from legal action by people or their Estates whose lives are prolonged against their will. Current case law recognises that a patient can refuse treatment and give end of life instructions to that effect. This area of law is relatively settled. To touch or treat someone who is capable of consenting but has not done so is an assault, even if treatment is necessary to save that person's life. This means that a valid decision to refuse treatment must be respected, even if that person will die. If a hospital nevertheless ignores an end of life request to not be treated, then the patient can likely sue. Even a medical treatment document signed without knowledge of the person's state of mind is considered valid. The court held recently in NSW that if a person signs a document freely then the refusal of treatment must be honoured.

In summary, end of life instructions need to be obeyed: if they are not, then a patient could possibly sue a hospital. This is clearly an issue of direct relevance to both Victorian hospitals and the Victorian government.

We are all capable of making decisions about our lives and we all do it every day. The end of life is no different, and we have – or could have – should have – the power in our own hands: to act or not to act.

In my essay *Undiscover'd Country – exploring chosen death* [Ginninderra Press 2015], I draw what I believe to be an important distinction between suicide and what I call chosen death. I ask that you consider those arguments, which are outlined below.

However much our society may campaign to prevent suicide among people when it is an act of spontaneous desperation, there is a distinction between such acts, and those that may be taken by people after measured and thoughtful consideration of the options available to them.¹

Precisely by taking the frantic panic and the imperative to act alone out of the discourse about the end of life, we as a society could help those in despair to seek the support that is offered. Then, rather than giving up hope or acting precipitously, some would reconsider. For others though, it is precisely because we may have no hope of living life as we once lived it, that the option to end our lives as we choose should be made available.

Human society has never sought to preserve the individual life 'at all costs'. We need to acknowledge this reality, and then discuss 'right to die legislation' in that context. Rationally and maturely, we need to examine the often hidden roots of our beliefs and practices about death, then change laws that need to be changed in order to allow individuals to make their own decisions about their own lives. We need to examine what 'suicide' is, and ask whether we in fact need new words for it in the context of 'end of life'; words with less pejorative connotations.

The definition of suicide is 'to kill oneself' but for many, that word 'suicide' is, has become, drenched in hopelessness and fear. It has become linked with people who act in desperation, without regard to the feelings of others and how they might be affected. Suicide is regarded as abhorrent by our culture, but does this negative connotation come as much from the guilt, regrets, anger and sadness felt by those left behind when someone suicides, as from the act itself? It needs to be remembered that for those who act, there is relief. Death *for them* is not the worst thing.

There are, after all, other sorts of self-death: one is the deliberate, thought-through act that others might see as reckless, brave, or selfless. Think of at least some of those soldiers in battles during the Great War like The Nek or Fromelles,² think of Mallory and his colleagues on Everest in the 1920s³, think of Captain Lawrence Oates's words '...I may be some time...'.⁴ It is paradoxical that, while refusing to consider rational death polices, our same

governments and religious institutions rigorously celebrate the deaths of thousands and thousands in wars, and the deaths of individuals in acts of bravery. The diaries of those soldiers show us that some knew exactly what was coming to them, did not avoid that inevitability, acted nonetheless.⁵ Were these 'suicides', as we understand them now, or in a way, chosen deaths?

Another sort of self-death is the death of self that occurs while we still live on. You may have seen it happen to loved ones: that living death, that 'disappearance' of a person who lives on but is somehow 'gone'. She may still speak, walk, but the core of her has been subsumed, has disintegrated, beneath the weight of illness, total occupation with treatments and medications, unhappiness, and the knowledge that her life is now pointless. This is the death of self that comes to some of us, where personality, skills, pleasures and even mild enjoyments are lost, where mere existence remains: this is existential suffering. Such suffering can come through physical illness, through medical treatments for those illnesses⁶, and through time – the death of friends and loved ones, loss of jobs, hobbies, delights, personal will. Some would call these losses 'mental illnesses', but that is simplistic and arrogant. Depending on what we each think and feel, some of us would just say 'I have had enough'. Should we be forced to live on because society says so?

We need new words to describe those times when the wish to die is simply a rational decision. A decision based on the facts of our own lives, and in the

knowledge that we, each of us individually has had enough, is in a place from which there is really no other escape, is done.

These decisions could be called chosen deaths: these are deaths made as a result of conscious rational choice by the individual concerned in their own, particular, set of circumstances.

These chosen deaths should be understood to be different from those spur-of-the-moment suicides. What if our society now had the maturity to acknowledge the difference, and the two distinct phenomena – suicide and chosen death - were not conflated as the same, and viewed as abhorrent, what then? Those of us who want to plan for death would be allowed to, unmolested and un-criminalized. For me, this is not a step too far. I do not sanction killing by anyone, except in a tiny number of circumstances, where the person concerned has left explicit and recently validated instructions. I argue for freedom of choice for us all as individual people to act as we each see fit.

So we can see that while suicide can be viewed as a social problem to be addressed by more and better-targeted resources devoted to specific programmes for youth, rural families and the long-term sufferers of some but not all mental illnesses, the concept of **chosen death** fits directly within the terms of reference of this Committee. It goes directly to issues around personal autonomy, personal control, individual peace of mind, and choice.

Unfortunately to date the Voluntary Euthanasia [VE] debate has been manipulated into a discussion, not about personal choice and personal action, but one largely limited to a question of when and indeed if Physician Assisted Death [PAD] may 'be allowed' to occur. Rather than let a person act *when and if* they choose, a doctor or doctors would be required *to agree to allow*, or *act* to kill. In addition this discussion is confined exclusively to those already terminally ill, and not far from death. The debate has thus become something of a power struggle about who gives **permission** to adults in decisions about their own lives. This is farcical on at least three grounds:

1. by definition terminally ill people are already dying; therefore the current 'debate' tinkers at the margins of the lives of people already suffering, adding yet more stress and pain to the person and their loved ones by adding onerous and unnecessary 'gatekeeper' requirements; and
2. let me ask you all: how many among you have ever met with your GP your medical specialist[s] and your psychiatrist [if applicable] *in the same room at the same time* to discuss any illnesses you may have, as the most recent iteration of legislative 'remedies' in the VE debate proposes?

I have never done so. I am sure in fact that my GP and specialists have never met to discuss my case. Existing structures of both hospital medical care, and the medical profession itself, make such a

proposition laughable. The ways in which doctors communicate with, and treat, patients is flawed fundamentally and needs reform. [Hitchcock 2012] While that is not your task in this Inquiry, those realities, and the VE scheme proposed in Richard di Natale's exposure draft Bill requiring 'permission' from three doctors in one room together is little more than an arrogant and frankly ludicrous regurgitation of earlier proposals, and one which marks a significant escalation in terms of degrees of difficulty in achievability.

3. Most importantly, many previous end of life Australian proposals, including the brief ***Northern Territory Rights of the Terminally Ill Act 1995***, leave the decisive action to end a person's life in the hands of doctors, not in the direct control of the people concerned, or only allow *permission* for the person to act themselves at the eleventh hour of that person's life.

My proposal in contrast is based upon the seeking and issuing of a prescription in the normal manner. It is based on an existing relationship between a person and her GP, and the *actions taken* subsequently *if any* – to have the prescription filled and then to take it – are solely those of the person concerned.

Rather than wait until I am nearing death, I may choose to elect death when I can no longer live the life I have. It is not a decision for the State or for any doctor or for politicians to tell me when I, and I alone, have had enough of life. This is, or should be, my choice, and one I

should be able to take peacefully and surrounded by loved ones if I choose.

My submission to you is that much of the proposed legislation that has been argued about fruitlessly, in so many different Australian jurisdictions, for more than thirty years, is unnecessary, patronising and wrong. Victoria has long been regarded as the most progressive state in the Australian Commonwealth - we have a notable record on public health innovations. It was the Victorian people who introduced seatbelt legislation and drink driving laws; we who first ran powerful road safety advertising. You have the opportunity to bring end of life discussion into the modern world, to offer Victorians real choice, and to move the community discussion to where it needs to be: centred around personal action, choice, decision, autonomy and agency.

Countless surveys and polls show that the Australian community is desperate for reform and change on this issue; many act illegally to achieve the death they want. Even without any public discussion of my proposal, a recent private *Essential poll* designed by me to test my proposal shows that 50% already support the idea. [*Essential Media [Private] polling, May 2015*] Imagine what the figures would reveal if any real public debate occurred about this proposal? You can make that happen by considering these ideas, and inviting real debate and discussion as a first step towards real reform that most Australians want.

Addressing the terms of reference directly:

1. 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, including the role of palliative care

The current *faux* debate is mired in a ridiculous numbers game about 'how many doctors does it take...'. All acknowledge that many doctors already 'assist' patients to their deaths. However that power is exercised currently in unofficial and unregulated ways. Importantly, that discretionary, unofficial power to 'assist' [that is kill] rests in doctors' hands, not our own.

Why in 2015 do doctors have this power? Modern pharmacology no longer requires such second hand intervention in most cases.

Others who will no doubt be making submissions to you have for many years run seminars which give us the code to use when we or a loved one is close to death, just to ease the way. **Why do we need this deceptive dance?**

While palliative care is indeed vital and must continue to be properly funded by government, it is not a solution for everyone. It is universally accepted that palliative care cannot relieve all suffering; even the peak body Palliative Care Australia admits publicly they cannot help everybody. While pain management and personal care are indeed essential, physical pain is not the only consideration in discussing end of life.

The existential suffering, the emotional, psychic pain, are just as important, and many of us will choose to end our lives before it is physical pain that dominates our existence

2. review the current framework of legislation, proposed legislation and other relevant reports and materials in other Australian states and territories and overseas jurisdictions;

The current debate and all past legislative proposals across Australia and most internationally do not address properly or comprehensively the issue of **personal autonomy**. Yet legal jurisdictions all agree that in all aspects of medical care *except* death, personal choice is paramount: autonomy is key. Yet even though we have the technology – a liquid to be drunk – we are not allowed to use it to:

- give us the same privilege and dignity we give our pets;
- allow us to die surrounded by loved ones if we choose; or
- allow us to die peacefully without violence; without vomit and faecal matter, or a bloody destroyed body, or a swollen hanged corpse, left for others to find.

Instead we must leave the country if perversely we are lucky enough to have a terminal illness, and go to Switzerland, if we can afford it. We must leave behind our home, our loved ones, and the familiar and comforting surroundings of places we love. Many do not have the wherewithal, monetary or psychological, to do that of course. Others do not have the 'right' diagnosis, but still wish to end their lives before such incapacities occur. So we are left with the answer tantalizingly close but illegal. So we become drug smugglers.

It is not right that failures to understand and to act by politicians are the only barriers to the personal autonomy at end of life that the majority of Australians want.

3. consider what type of legislative change may be required, including an examination of any federal laws that may impact such legislation

The legislative changes required to make this proposed system workable include, and may in fact be limited to:

- re-legalizing Nembutal, and regulating its sale by prescription through chemists as for other pharmaceutical products to those aged 60 and over; and
- removing the law that makes any other person present at the time of an individual's death liable to charges of assisting a suicide.

The Committee knows that suicide is not illegal. Chosen death should also be legal.

The Committee knows that Victoria has existing laws proscribing:

- obtaining a prescription fraudulently;

- coercion,
- blackmail,
- criminal assault,
- murder.

All the required protections are in place to prevent, investigate and punish any person who:

- obtains Nembutal [or any other drug] by deception,
- steals it from someone else,
- tries to force or coerce someone to use it, or
- administers it to someone against their will.

The Committee of Inquiry has been convened to discuss provisions for the end of life. We are discussing decisions to be made by mature adults who do not require, and in fact reject actively the notion of 'protection' or 'guardianship'. There is no requirement for gatekeepers; in fact the very idea is patronising and insulting. An adult is capable of decision-making on this issue, as on all other personal health matters.

In its deliberations about this most human of subjects, the Committee will take into consideration that many things which are now commonplace were once considered immoral; some were also illegal:

- universal suffrage,
- contraception,
- divorce,
- de facto relationships

- abortion,
- surrogacy;
- artificial insemination
- organ donation and transplant
- homosexuality and
- gay marriage [nearly there].

To choose to act to end one's life in consultation with **but not with permission from** our GP, counsellors, loved ones and friends is, at the end of the day, just one more human decision. Those who persist in arguing, as does the current federal proposal, that doctors must be the ones to administer death, or to permit us to act, offer us little but a high dose of paternalism. Their 'fears' that 'people who are rational might end their lives because of misinformation and misunderstanding' are condescending and patronizing: the simplest, indeed the only way to prevent misunderstanding or confusion are to explain new laws and how they work. This is not, or at least should not be, beyond the wit of government.

Today chosen death can come with violence and in secret, or in concert with loved ones and in peace. This is a moral choice; an ethical decision and it is personal.

While there remain some among us who eschew some medical interventions, or divorce or gay rights or indeed women's rights, these are not the prevailing legal principles nor the human values of our society and community.

Nevertheless no one in Victoria can be forced to have an abortion or to donate their organs or use contraception, nor should they be. No doctor can be forced to perform treatments or issue prescriptions to which she is opposed, and nor should she be.

In exactly the same way, no person should or would be forced to end their lives: that would constitute a criminal offence with harsh penalties. To argue, as some do, that to lose a single person should they take a hasty decision or being murdered against their will is 'a price too high' to pay for the freedom, choice and peace this proposal would bring to so many, is to argue that in order to prevent any person dying in a road accident, no one should ever drive. It simply does not wash, and implies that those making that case have some sort of superior 'guardianship' role over us **to which no one has appointed them.**

I am of course completely in favour of high quality palliative care and aged care, and support completely existing funding for these programmes. Indeed I believe that more and better-targeted spending should be devoted to them. Nothing in this submission argues for fewer resources to be devoted to these vital services.

For once and for all, there is no 'slippery slope' argument about end of life care. No evidence of it exists anywhere. [White and Willmott 2012; Douglas White and Willmott, 2013] Extensions of voluntary euthanasia [VE] provisions in some overseas jurisdictions constitute carefully thought through and

democratically voted for inclusions such as terminally ill children, or those who are now incapable of deciding but previously expressed such a wish.

In conclusion I submit that like all of life's important decisions, in Victoria today the decision to choose death is a personal one. At the moment, while most people end up accepting what help they are offered at the very end, any decision to 'go earlier' means that choice is either violent or secretive or both. Or it is peaceful but results from an illegality - either one where a doctor acts to over-prescribe *at the bitter end*, or where a person takes the Nembutal she has obtained unlawfully, when she chooses.

This Committee can help to make death peaceful and lawful.

My proposal for legal regulated access to Nembutal would give thousands of people peace of mind as they age. **It is also important to note that those who are well placed to know estimate that 'glancingly few' would actually use their Nembutal. [Ryan 2014].** Nevertheless the fact that they *could* get the prescription, and would perhaps one day purchase the drug itself and store it somewhere, would offer many peace of mind as the end of life approaches.

The very idea of that possibility, that potential peace of mind, will of itself contribute positively to the health and well being of us all, as we age.

We will have control in our own hands even if we never decide to use it.

We will have the very personal autonomy the law offers us in all other medical decisions but not yet this one.

We might wish that death would come ‘when our back is turned’ as the writer Lionel Shriver put it so memorably in an ABC discussion of this issue in 2014. [ABC Television, Big Ideas, February 2014] But if death does not visit us so kindly, or indeed does not come early enough to prevent our existential suffering, we will have the means to prevent the things we fear. No institutionalisation; no enfeeblement, no long-drawn-out ‘heroic measures’ for us, no decisions taken out of our hands, no personal agency and autonomy lost.

Thank you for your attention. I request and would welcome the opportunity to address you, either publicly or privately, in order to expand on these ideas, to demonstrate how the system could work, and to assist in helping to overcome any perceived practical or philosophical problems. I look forward to discussing these ideas and any questions or reservations you may have about them with you in person.

Debora Campbell



References and Endnotes

References

Bob Douglas, Lindy Willmott and Ben White, January 2013, The Report of the Roundtable Discussion arising from this report, downloaded June 16 2015 from http://www.australia21.org.au/wp-content/uploads/2013/08/J2056-Assisted-Death-Report_WEB.pdf

Essential Media Private Polling May 2015;

Karen Hitchcock Last Resort *The Monthly* July 2012

Dr. Christopher Ryan, the Director of Consultation-Liaison Psychiatry at Sydney's Westmead Hospital, an Honorary Associate of the Centre for Values, Ethics and the Law in Medicine and a Clinical Senior Lecturer at Sydney Medical School, has published widely on suicide and depression. He was a supporter of the Northern Territory ROTI law which included a psychiatric assessment requirement for those choosing to die. Asked his opinion on the likely rate of take up, should a right to die option be available, he commented, 'One of the things I find interesting about objections to legalization of euthanasia/physician assisted suicide is the concerns among opponents that legalization will increase the number of people dying. In fact, vanishingly few (but not no) people want to afford themselves of such laws. Most people (despite their inclinations when healthy) want only to live when they become sick. Of course some people do want to die, and why would I stand in their

way, but not the overwhelming majority. A larger percentage like having the option, but will never take it up.'

Professor Ben White and Professor Lindy Willmott, November 2012, Health Law Research Centre, Faculty of Law, QUT, *A background paper How Should Australia Regulate Voluntary Euthanasia and Assisted Suicide*, November 2012 downloaded June 16 2015 from <http://www.australia21.org.au/wp-content/uploads/2013/08/ASAssisteddyingBP1.pdf>

A comprehensive summary of international jurisdictions, which allow voluntary euthanasia in some form.

End Notes

¹ My proposal limits those eligible for legal Nembutal to those 60 or older. The entitlement of one age group [60 and over] but not another [under 60] is common enough in existing law – driving age, drinking age, voting, eligibility for superannuation. Provision should also be made for younger people on a case-by-case basis, after extended consultation with their GP, and for children with terminal illnesses.

² Bill Gammage, *The Broken Years*, Penguin, 1974. See for examples pp. 99 to 101.

³ Wade Davis *Into the Silence: The Great War, Mallory and the Conquest of Everest*, Bodley Head 2011, p.554 and p.573. Davis' thesis is that, having experienced the horror of the Great War at first hand, many of those on these early expeditions, including Mallory himself, had a degree of fatalism which made life-threatening challenges seem of little or no consequence in the greater scheme of things.

⁴ At least according to Scott's diary. See http://en.wikipedia.org/wiki/Lawrence_Oates downloaded March 4 2014

⁵ op cit Gammage 1974

⁶ *Vital Signs: Stories From Intensive Care*: by Ken Hillman, UNSW Press 2009; *Saving Life or Prolonging Death* Charlie Corke, Erudite Medical Books, 2010; *Dying for a Chat* by Ranjana Srivastava, Penguin, 2013; *Tell Me the Truth* by Ranjana Srivastava Penguin, 2010..

'Undiscover'd Country...' exploring chosen death

by Debora Campbell

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More than 70% of Australians want changes to the laws relating to death. A Bill before the national Parliament would require us all to get the permission of a psychiatrist.

What does this Bill tell us about the euthanasia debate in Australia?

What does it say about the scope of our political discussion?

What can we learn when we consider that the current debate revolves *only* around the role of doctors, and does not propose an active role for actual people?

This essay proposes a radical reform of the way we think – collectively and individually - about death in Australia.

It details a specific policy change to the law about personal death that would put power into the hands of individuals – each of us. It dispels some purposefully proselytized myths about euthanasia laws here and elsewhere in the world, and reveals our mainstream politicians as cowards and hypocrites.

This examination of the euthanasia debate in Australia explores our individual and collective rights, entitlements and responsibilities to ourselves, to each other, and to the wider community. The essay pulls no punches in exploring our apparent abhorrence of suicides of all sorts, and lays the blame for inaction firmly at the feet of mainstream politicians who have refused to act.

Unlike many writers on the subject of euthanasia, Debora Campbell is neither a doctor of medicine, nor someone whose death is imminent – as far as she knows. Nevertheless the subject of death and how our society deals with it, or does not, has interested her for many years. Current maladroit legislative attempts to address the right to die seem to her ridiculous. The real reasons for such mortal confusion should, in her view, to be brought to community attention.

For 25 years, Debora worked in intelligence, industrial relations and indigenous affairs in universities, and in the private and public sectors. She holds a PhD in business and economic history, and runs a small business in Deans Marsh Victoria where she is active in community affairs locally. She has written business book reviews for the mainstream press, contributed to local newspapers, and self-published a history of a local community enterprise. She is an informed but highly sceptical consumer of news media, and is passionate about observing and assessing how political and social decisions being made now will affect the future for us all.