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Inquiry Name: Inquiry into End of Life Choices

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A submission to the Committee examining END OF LIFE CHOICES

The Current Situation

In the first 4 months of 2015, 34 Australian women died from domestic violence. This has been universally declared a 'crisis of epidemic proportions'. But in that same time, the best available statistics suggest that more people had the misfortune to die often protracted, tortured deaths from naturally occurring diseases. Unlike the complex, multifactorial issue of domestic violence, compassionate legislation could immediately prevent much of this senseless suffering.

I have worked for 3 decades in Australian health, primarily in Anaesthesia but also some Intensive Care, General Practice and Emergency Medicine. I don't use the word 'tortured' lightly but I believe it is an accurate description of the dying process in some situations.

Examples I have witnessed include: Irremediable pain when cancer fractures multiple bones, progressive paralysis of Motor Neurone Disease causing slow suffocation, immobility and incontinence from cancer eroding the spinal cord and just the overwhelming existential suffering and exhaustion of many end-stage diseases.

When our time comes, the chances of any one of us dying a tortured death are probably less than 1%, but the chances every year that someone in Victoria will suffer horribly in dying are 100%. There is no way around this statistical fact, because disease can be cruel and medicine will never be perfect. No-one's at fault, it's just what happens in any large population, despite the best will (and palliative care) in the world.

Oregon US has had legal physician assisted suicide for 18 years and has averaged about 50 deaths per year in that time. Hence Victoria, with 50% greater population, might expect to average 75 cases yearly, which amounts to less than 1 in 500 of the approximately 40,000 total annual deaths. Legalising Voluntary Assisted Dying (VAD) in Victoria would permanently prevent 1-2 tortured deaths every week.

There is massive (consistently around 80%) community support across Australia for legal VAD, when proven safeguards apply. Why then do parliaments around Australia repeatedly reject VAD legislation? The answer is that well organised, reactionary lobby groups, led by the Catholic Church, exert a disproportionate influence on political decision making. If concerned about a voter backlash, even from a small, noisy minority, politicians tend to take the conservative option.

Like many ethical debates, there will always be strongly held, conflicting beliefs, however the essence of a free society is tolerance of differing viewpoints, provided they are reasonable and don't harm others. When medical treatment has nothing more to offer, the issue of end of life choices becomes more personal and philosophical than medical. At this stage no one person or organisation can tell terminally ill, fully informed and aware patients what is 'best' for them.

If VAD was legalised, the lives and deaths of opponents to the legislation would not be altered in any way. They will remain free to endure the vagaries of their illness however they wish. Proponents, on the other hand, will be free to decide for themselves when they have suffered enough.

Ironically it is the conservative side of politics which advocates less interventionist government, which most often obstructs personal rights in end of life choices. An example of this is the current Coalition Federal Defence Minister and lay Catholic, Kevin Andrews, overruling the Northern Territory's Rights of the Terminally Ill Act in 1997. It is also ironic that politicians, normally so

attentive to polls, should not seek to capitalise on such extraordinary levels of community support on this issue.

Some points relating to the Committee's terms of reference:

1. Legal changes are required to protect both the patient's right to control their own life and death, and the doctor's ability to safely implement the patient's wishes

I had a fully paralysed patient on life support with end stage neuromuscular disease who could only communicate through eye movements. Once he realised he would never get off the ventilator, his mental status deteriorated to extremely fragile and he repeatedly indicated that he wished to die. His eyes would well with tears on mention of his home, family and pets.

The problem with ceasing artificial ventilation was that he would need almost an anaesthetic to overcome the feeling of suffocation as he died. Family members expressed strong opinions ranging from 'it's his life and his choice' through to 'nobody should play god'. If artificial ventilation is ceased as strong intravenous sedation is given, causing rapid death, some may believe this to be murder.

In Intensive Care Units people from all cultures and beliefs are suddenly thrust into life and death situations often with no prior experience. It's a high tech, confronting environment and people respond in many ways: fear, anger or false expectations are common. The potential for litigation is always present and may influence outcome, as in this case where a conflicted family could not reach a consensus and whatever medical staff did would be criticised. The patient remained on life support for 11 weeks until he died from pneumonia.

I can scarcely imagine what went through his mind, immobilised, staring at the ceiling for months, unable to say where he was hurting, with tubes in his windpipe, arm, stomach and bladder, 24hr machines and alarms, no hope of recovery, begging to end it all and finally an awful septic death.

Current laws failed to protect both this patient's right to control his own fate, and the medical staff's freedom to implement his wishes.

2. Palliative Care and End of Life Choices including VAD are both equally important

Dying patients I have seen universally want a frank discussion of their prognosis and treatment options, and appreciate candour and respect. Palliative Care allows them to live comfortably with their illness for as long as possible, but there is a failure rate, acknowledged by all Palliative Care physicians, of probably less than 5%. Patients often fear the manner of dying more than death itself and knowing they have control over the time and manner of dying, if it becomes unbearable, brings great comfort. Safe in the knowledge they have control, some have then felt empowered to undertake further treatment, prolonging both the quality and duration of their lives and demonstrating that palliation and legal VAD can act synergistically.

In Oregon one third of all the lethal sedation scripts written for terminally ill patients are never used. Knowing that a tranquil death is always possible helps dispel fear as the disease process progresses and lessens the need to take drastic preventative action. This has been borne out in Oregon where legalisation of Physician assisted dying has caused a statistically significant reduction in the elderly violent suicide rate. Statistical analysis shows a 98% likelihood that this reduction did not happen by chance. It's extremely likely fewer elderly Victorians would hang themselves if VAD was legal.

Palliative Care and VAD are equally indispensable in the dying process. This makes good sense because VAD would primarily become a consideration after palliation has been tried and failed. Palliative Care and VAD as an end of life choice are complimentary, sometimes synergistic and do not usurp each other's role.

3. Current Laws are turning some elderly into "grey criminals"

My already disabled mother died several months ago from a second stroke which left her unable to cough, speak or swallow, and hence facing death by starvation or pneumonia. She repeatedly pulled out nasal feeding tubes and wrote "euthanasia- help me please" in her barely legible writing. Because my family were united behind my mother's wishes, the palliative care team felt safe to give a lethal morphine and midazolam sedation, at our request. Dying still took five days but awareness and suffering ceased. We were lucky to know how the system works and to find a like-minded palliative care specialist. Other families with less insider knowledge may not be so lucky and could easily find themselves in a palliative care hospice with a more faith-based agenda, offering less intervention and more suffering. Luck or insider knowledge shouldn't be necessary for a good death.

If my mother had not promptly received the palliation she wanted, I would not hesitate to take her home, surround and farewell her with family and love, give her enough sedation to fall deeply asleep and then end her life with anaesthetic drugs. I would dread such action, but she's been a wonderful mother and I absolutely refuse to stand by and watch her starve. In doing this, I could incur a murder or, at best, assisted suicide charge, plus a criminal record and gaol. Many elderly Australians who have probably never broken the law in their lives, are currently assisting loved ones to die, importing illegal lethal sedatives from countries like China or Mexico, appealing for Nembutal online or making their own barbiturates because the current laws give them or their loved ones no guarantee of a peaceful death.

If I were not an Anaesthetist, I may well attempt to obtain illegal drugs online or alternatively seek out a compassionate, respectful doctor such as Dr Rodney Syme. A majority of Australian doctors are in favour of VAD, but you don't know in advance who they are, and it could be crucial.

This legal limbo land around suicide and assisting suicide raises further questions:

Suicide is legal but assisting someone to suicide is a criminal offence, attracting gaol terms of from up to 10 years to life. To date, there is no legal precedent to define 'assisting' in the context of suicide. Are you 'assisting' suicide if you sit by the bed and provide emotional support? Are you assisting death or even murdering a paralysed patient who can't lift a lethal sedative to their mouth, when you lift it for them at their request?

The consequences of this legal uncertainty are that some patients have committed suicide alone, so as not to implicate loved ones, or done so earlier than they would otherwise, for fear that they may become physically unable to drink a lethal sedative. In the absence of illegal drugs, the commonest method of suicide amongst elderly Australians today is hanging. It's hard to imagine both the loneliness and desperation needed to do this, or the horror of finding a loved one hanged.

4. Legislation allowing VAD as an End of Life Choice has been working successfully overseas

As a legal framework guide, Australia is fortunate to be able to examine long-running, proven VAD legislation in practice overseas. The hard work has already been done. Oregon, having the longest running Death with Dignity legislation, with proven safeguards and thorough record-keeping, provides an excellent model. It has overcome Supreme Court legal challenges and gained wide acceptance, whilst disproving the dire predictions of 'slippery slopes' and vulnerable elderly abuse.

In the words of Oregon Senator Ginny Burdick, who has been in office for almost the exact period of time that Oregon has had legal VAD: "*The law has worked beautifully. The scare stories were just that: scare stories based on nothing. None of the terrible things that opponents predicted has ever come to pass.*"

5. Some additional considerations:

For Life Insurance purposes, where an exclusion clause for suicides may exist, cases which have followed the full VAD eligibility protocol should be treated as natural deaths.

Publically available, compulsory data collection and analysis should accompany VAD legislation.

Protocols for temporary storage and maybe locking up lethal prescription drugs in the home need consideration.

As with abortion, doctors must be free to opt out if they wish. In the vast majority of cases a lethal sedative can be swallowed by the patient. If this is physically impossible a doctor or third party could be authorised by the patient to administer the sedation.

Death is still a taboo subject in our community making all aspects of dying harder to deal with. Publicity and education campaigns on VAD would help more people to have a good death.

There is still fear and uncertainty in our society about the introduction of 'euthanasia', some of it deliberately incited. It is not fully realised how tiny the VAD legalisation 'target' actually is and how stringent the eligibility criteria are for say an Oregon style system. The community needs to know that VAD is completely irrelevant to anyone who is not fully aware, fully informed, terminally ill, actively and repeatedly requesting VAD both orally and in writing, and prepared to wait the cooling off period. Dementia for example has nothing at all to do with VAD.

Finally, the stumbling block for VAD legalisation on the forty odd occasions that bills have been introduced into parliaments around Australia has always been political. Whether it's financial, traditional, religious, not wanting to align with the Greens, peer group or party pressure, it's baffling that so few could hold such sway over the political process for so long. As the baby-boomer population spike ages and the death rate rises, the issue of individual rights to control one's own life and death will become irresistible. The overwhelming wishes of such a huge majority will prevail, because control of one's own life and death is a basic human right, like gender equality and free speech.

Many thanks to the committee for the opportunity to make a submission.