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Voluntary Assisted Dying, an evidence based approach

It is no longer reasonable, morally correct or medically right to state, as many prominent politicians and some notable doctors assert currently, that Assisted Dying (AD) laws are unsafe. Those who do, say it is not possible to create laws that protect the vulnerable in our community - those who are actively dying from incurable illness without rational prospect of prolonging life or reducing suffering, are simply wrong according to empirical evidence.

There is nowhere left to hide, Ms Berejiklian, Mr Secord, Mr Foley, Ms Keneally, Dr Gannon and Prof Somerville.

The Australian Medical Association (AMA)], which some refer to as Australia's "peak" medical body, is opposed to VAD for the same reasons. Yet, like so many of our politicians, does not take an evidence-based or patient-focussed approach. As a professional body, they are surprisingly oblivious to the evidence.

The evidence clearly refutes there arguments.

Let's do something a little different: if we strip back the religious objections (many don't share your views), the moral assertions, the straw-man arguments and plain ignorance of the data, we can take a patient-focussed, evidence-based position.

We should be approaching this discussion with our patients (as well as legislator or medical colleague) in the same way as we discuss such things as the right blood pressure medication or the right operation for that bad back - on the basis of evidence.

When patients approach a doctor, they deserve the best evidence without fear or favour. In fact, under the Australian Medical Council's code of conduct, if a doctor has a set of personal beliefs that affect their ability to give objective advice, they need to disclose it to the patient.

If we, as doctors, regard our role as facilitating good decision-making by competent adult patients, then we must do two things:

1. Provide comprehensive information about their situation, either personally or by enlisting other experts and
2. Guiding them through their decision making process as objectively as possible.

We must then support what they choose. That's how it works. That's what people want.

The most common error made against AD is that it opens the door to abuse. They say that the vulnerable could be influenced by those seeking to gain from the patient's death.

The evidence

The large weight of international evidence refutes this claim. The curious phenomenon is that these prominent politicians and doctors seem to be ignorant of the simple evidence. It's not as if the evidence is hard to find. There are also plenty of experts to assist in finding it.

Australia is in a fortunate position in late 2017 with two state Parliaments (NSW and Victoria) are due to decide on the fate of AD legislation and two others will follow soon (WA and Qld).

This country does not have to re-invent the wheel. There are currently fourteen other jurisdictions around the world where AD is legal. Switzerland has been doing it since 1942 and Oregon since 1997. These countries are just like us. In Holland, it has been legal for 15 years. More recently, VAD has become legal in Canada (2016), California, Washington State, Washington DC, Vermont, Colorado, Montana, Belgium, Luxembourg, Columbia and more areas are actively considering this form of care. Germany has access to VAD.

These sources of objective information about VAD have been freely available in medical, legal and political literature for some years, although in the last 12 months more has been published. Few in the anti-AD campaign seem to have accessed it.

Here it is:

In 2016 the Oregon data was published (1) and presented at a Palliative Care/Oncology conference in the US. The report (not the first from that state (8)) found no evidence of abuse of vulnerable patients. In fact, those people accessing PC were generally, white, well-educated and elderly. Nor did the numbers change greatly from year to year. There was no evidence of a so-called slippery slope, where the rules and access became more lax as time passed.

Additionally, in 2012 Justice Lyn Smith of the Supreme Court of British Columbia was asked to rule on a case where the applicant sought AD. In her extensive judgement she could find no evidence of abuse in jurisdictions where AD was legal. This led to her writing to the Canadian national legislature, giving them 12 months to enact an AD law. Canada now has a functioning AD law (2).

In 2016, the Victorian Parliamentary Inquiry into AD (3), commissioned by the Andrews government, reported after an exhaustive 10-month assessment. This included literature reviews, submissions from experts and study tours by Parliamentarians to several jurisdictions where AD is in operation, like Oregon. The report found no evidence of abuse of vulnerable people worldwide. In their comprehensive report, they found no evidence to justify the conclusion that these laws could not be safely implemented.

In 2007, the Journal of Medical Ethics (8) reported on the then 5 years of experience with AD in the Netherlands. Once again, there was no evidence of abuse.

OK so can we stop that argument now?

No-one denies elder abuse occurs, like child abuse sadly in every community. That is not what we are talking about with VAD. If a person was going to exert pressure on a vulnerable person, they are hardly going to do it through an open, transparent medico-legal process like the ones proposed in NSW and Victoria and are operating around the world. They would, I submit, do it in the dark, away from the public eye.

This is not what we are talking about.

The Assisted Dying Consult

The medical consultation would look like this: a patient who is known to their primary medical practitioner, suffering towards the end of a terminal illness would access care. In NSW the legislation stipulates that the consensus amongst their treating team would be less than a 12 month survival expectation.

They would ask about their options for ongoing care and symptom control. Amongst the suite of options presented to them would be a discussion around AD, Palliative Care or ongoing active treatment. There may be several conversations with their team over a period of time. Involvement of family members would be encouraged and facilitated, as with any other large decision. Open disclosure of all options, pitfalls, advantages, costs and likely or foreseeable outcomes would be discussed. The team would make an assessment about the patient's competence (medially speaking) to make the decision. The NSW iteration of the proposed legislation requires a psychiatrist to verify the patient's competence, Victoria does not unless there is uncertainty.

The patient would then make a decision in a calm, unhurried manner.

When one speaks to patients in these situations as a doctor, I am constantly surprised by their levels of awareness, knowledge, practicality and courage. As Atticus from *To Kill a Mockingbird* tells Scout, his daughter

“You never really understand a person until you consider things from **his** point of view...until you climb in **his** skin and **walk** around in it.”

There are other unsubstantiated arguments doctors and politicians invoke against AD. There is a perception that it will somehow negatively affect the doctor-patient relationship.

As far as I can see, they feel that speaking about AD with a patient is somehow taboo and that we should not go there. Yet as doctors we offer options to patients all the time, as is our job. Some of the options we offer are unpalatable. Some are desired yet never spoken about. To pretend that this aspect of end of life care does not exist is simply denying a fact. Additionally, as with many aspects of care, if we do not speak of it then patients will frequently take matters into their own hands.

During the Victorian Parliamentary Enquiry, the state coroner gave harrowing accounts (9) of the numbers and details where people had killed themselves - or attempted to - by their own hand when confronted with a terminal diagnosis. Hangings were the most frequent although the use of firearms was predominant in rural Victoria. The recent suicide in this manner by a WA Palliative Care doctor, alone in the country, exemplifies this horrific situation.

So, again, what is the evidence?

Doctor-Patient Relationship

In fact, at least four studies (4,5,6,7) have looked at the effect of AD discussions by a doctor on the patient's perceptions of their professional relationship. These studies found, perhaps surprisingly to some in my profession, that AD discussions DID NOT make the patient trust the doctor less or feel that it imp[aired their therapeutic relationship. The most recent study, published in the *British Medical Journal* in 2005 found that the relationships were enhanced and increased patient satisfaction.

And why should exploring options or discussing the peaceful and dignified way to die surrounded by their loved ones at a time of their choosing be in any way negative between a patient and their medical advisors?

It should be remembered that, for some people with terminal illness death is not the worst outcome. Continued existence with no quality is perpetuation of misery.

Palliative Care

Some patients elect for Palliative Care. In the majority, of cases this is a good option. PC is now a sophisticated specialty with an advanced training program and access to their own hospices (Although 60% are Catholic owned in Australia).

However, like every medical specialty, there is a failure rate. Palliative Care Australia's own estimates range from 5-8% patients where they are unable to successfully control symptoms. This corresponds to international figures. The Oregon experience shows that the commonest reason for patients accessing AD was not pain but poor quality of life. Palliative Care are limited in the ways that this can be addressed.

There is no medical specialty that claims to have all the answers. Some patients do not wish to enter Palliative Care, even after a full discussion of the specialties' scope and services. We do not force people to have hip replacements or brain surgery and there is no moral justification for funneling all terminally ill patients into PC against their wishes. This current state of affairs forces people to take matters into their own hands as we have tragically seen.

The two forms of treatment co-exist in the international jurisdictions.

So, let's not re-invent the wheel. There is nothing different here to those parts of the world where AD is legal and functioning well, addressing a significant need, to Australia.

To those politicians and doctors who are not aware of the evidence around the world yet still loudly proclaim opinions - shame on you. Opinion without evidence, especially that which contradicts freely available evidence, is not to be respected.

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