

If you are in the room today, I'll take for granted there is a high chance you may have very personal stories in relation to death.....

You might have experienced death directly as a first-responder - a medical practitioner - a family member - or as a politician.

Either way - no matter what your title is - thanks for coming today - and thanks also to the media that has kept a spotlight on the issue of VAD.

So.... we are here today to talk about broadening eligibility for Voluntary Assisted Dying in the A.C.T. It's a difficult topic but it's one that must be discussed. I'm going to try to remain objective on getting legislative change - however - I genuinely hope today is cathartic for some in being able to discuss these topics more openly.

I came to know about VAD late by comparison to some in the room. During 2018 I was an attendee at parliament house to watch one of the many attempts to restore territory rights be defeated. I remember being so infuriated at the inhumanity that I could barely concentrate at work the next day.

At that point in time - I actually had barely any hope for VAD - let alone legislation to help people who had lost decision making capacity. I've since learnt other countries around the world already had incredibly merciful laws that allowed patient autonomy - even in the most complex of medical circumstances.

I thank my lucky stars that A.C.T has legislation to be implemented next year and want to express my personal gratitude to Tara Cheyne and Marissa Patterson for all of their work in recent times..... as well as all of the other advocates out there. In particular Tony Whelan, Jeanne Arthur, David Swanton, Roy Harvey and all members of Canberrans for a Good Death.

Despite being new to VAD advocacy - some might say I have an in-depth knowledge of what an untreatable terminal illness can do to a person. The result in the case I witnessed was terminal sedation for nine days to a person.

They had been in a vegetative state for months if not years..... worn nappies with endless urinary tract infections for years..... had a rugby head gear on to avoid injuring themselves and weighed less than 50 kilograms. They had long since lost their decision making capacityand had expressed many times over the 7 years of illness they just wanted to pass peacefully.

I've been quoted in the paper as saying the care in these final days was the best care money could provide in the A.C.T which is a view I have taken on certain days.

On other days - I'm also conflicted in thinking 9 days of terminal sedation is potentially medical negligence or a breach of the Human Rights act. I'm perfectly happy to unpack these issues with anyone willing to listen.

Either way - I'm not going to wait for another 5-6 years to wait for the results of a review into V.A.D to then see eligibility widened for sufferers such as these.

We need to see broader eligibility for VADand we need to see it now.

I'm convinced there can be a better and more merciful system. Our survey results collated by Canberrans For a Good Death unequivocally confirm the community would support such a system.

Indeed - people I speak with are surprised that it is not there already.

If you are an election candidate and you have not got this message yet - please come talk with me. The community wants this.

If you are elected on their behalf of the community - Canberrans For a Good Death intends on holding you to this.

In the broader picture - these issues go much further than just Canberra. Knowing that A.C.T has a Human Rights Act. and that the Human Rights Commission made a submission for wider eligibility in VAD - the rest of Australia is watching us. I've just this week received correspondence from as far as Scotland and Canada seeking updates.

Canada themselves have found merciful - but legal ways to handle situations whereby a person's death may not be imminent - but their diagnosis is such that science cannot help them to avoid suffering

Canada has also navigated situations where the sufferer may lose decision making capacity at the later stages of the V.A.D process.

I think this is an incredibly important point to remember moving forward.

I doubt there is anyone in this room including myself who would not donate to scientific research.

Having said this - until science catches up with cures - or even treatments for some of these diseases - we are bound by the Human Rights Act and we need to think about this in support of widening VAD eligibility.

It shouldn't take a sufferer to launch legal action for discrimination in order for a modern jurisdiction such as Canberra to step up and support these people to have their wishes respected.

I truly hope as a community we can make this happen.