Submission Cover Sheet

End of Life Choices in the ACT

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To Whom It May Concern:

I wish to add my voice to the discussion around Voluntary Assisted Dying in the ACT. The time has come to review the commonwealth legislation concerning VAD in the territory; it is therefore also time to discuss the pros and cons of eventually legalising VAD in our small corner of the country.

As a grandmother, a nurse with 39 years of hands-on experience in the ACT, and a daughter/-in-law to 4 wonderful elderly members of the community (all now no longer with us), I consider I have a vast wealth of experience witnessing the extremes of the human condition.

My first question is: what can be done to give the ACT power over its own decision-making process? Enough time has elapsed, the world has moved on, we're in an entirely different place than we were when this commonwealth legislation was enacted... people power now needs to bring us sovereignty over our own end-of-life decisions; any other outcome will soon become a glaring anachronism, and will deprive the ACT community of a basic human right: the ability to make our own decisions about how we die. I understand that the first steps in the process have begun, but we need to maintain the momentum and do what we can as a community to support our government to carry this through to its logical conclusion. I for one will be actively behind the push, every step of the way. I can only hope we have strong leadership here, and I note the efforts of Tara Cheyne and Andrew Barr in this regard.

As for VAD itself: I have long held (since I was about 18... I am now 63) that VAD should be a basic human right, a matter of choice for the individual. As the years have progressed, I have witnessed the deaths of countless patients, as well as two parents and two parents-in-law. These experiences have only strengthened my belief that an individual's death is not the sacred domain of small religious fringe groups; it is the private business of one individual, and that individual alone (notwithstanding they often have family support). Every human being is born and must die... pretty simple. So how have we made death such a difficult and complicated process in this country? Unfortunately we have ignored the wonderfully humane example of several enlightened European countries, and finished up being held hostage to a small minority in the community who wishes to dictate the terms of our own individual deaths. Where is our compassion? It's illogical, it's inhumane, it's utterly unfair.

As a nurse, I have seen the wonderful thing that is the Palliative care team, on countless occasions. Where would we be without them? But of course, the number of people whose deaths I have witnessed over the years has taught me that a significant proportion of the community would certainly have chosen VAD if it had been available. Many's the time I've had terminal patients (and their loved ones) ask me to put them out of their misery; this is a distressing situation to experience and navigate. It's high time we addressed it. Physical distress is not the only consideration; we must address the issue of dignity in death. Being forced to prolong one's death deprives certain individuals of basic human dignity, and this is distressing for those individuals. It must be remembered that the 'sacredity of life' simply isn't an issue for every one of us, so we must all be allowed the dignity of dealing with life's end in a manner of our own choosing.
As a daughter-in-law I have seen two elderly parents-in-law receive the benefits of the ACT Palliative Care Team, and I couldn't fault them. These two elderly people held lifelong religious beliefs, and were opposed to VAD, so it was the perfect outcome in two difficult deaths: the 'best possible deaths' for those two people.

But as a daughter I witnessed two deaths that dragged on far too long, in two elderly people who had no religious beliefs at all, and I know that the mere presence of VAD would have given them both great peace of mind even if they had not chosen to take up the option. And here is the nub of the issue: it's all about choices. If you know you will have a choice, the peace of mind is there from the very beginning (in fact for years beforehand)... you may never use it, but you will be reassured by the fact that when the end is near you WILL have a choice. For me this is the beautiful simplicity of the issue... it's all about peace of mind. Pal Care may well be able to assure me, a terminally ill human being, a pain-free death, but what if that's not what I want? What if I simply want to die when I'm ready, at a time of my own choosing? And what if I get to that stage in my life where death is all I want, but some small minority group wants to stop me? The answer is: I'll be extremely disappointed and will not die a good death. And my relatives will know this too, and will also be very disappointed. This is all completely unnecessary. Suffering is not simply physical, it is mental as well, and this is often overlooked by Pal Care specialists. Let's follow the example of enlightened countries where VAD has proven very successful, where there have been no glaring disasters, and where people can die good, humane deaths at a time of their choosing. If we have the good sense to alleviate the suffering of beloved family pets, why do we make our own species suffer, simply because we can?

So my final plea is that we start this conversation now. And I thank Tara Cheyne for getting this ball rolling, and not a minute too soon. Do we want death with dignity? Do we want death without mental and physical suffering? Do we want a small minority to make our fundamental life and death decisions for us? What are the traps and pitfalls? How can we do this humanely but safely? And what about the small minority of patients (and their families?) who die dreadful, painful deaths because Pal Care simply doesn't cut it? We need to start talking as a community. If Victoria can do this, then so can we. We need to give VAD a chance.

Yours faithfully,

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