LEGISLATIVE ASSEMBLY
FOR THE AUSTRALIAN CAPITAL TERRITORY

SELECT COMMITTEE ON VOLUNTARY ASSISTED DYING BILL
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Submission Cover Sheet

Inquiry into the Voluntary Assisted Dying Bill 2023

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End of life and Dementia

1. End-of-life plans should not be only about what carers are **not** allowed to do (resuscitate, feed etc) but should also include what a patient wants them to do.

2. End-of-life plans should be permitted to include instructions to carers while individuals are cognitively able to articulate their wishes consistent with the principles of free, prior and informed consent.

This should be an option. Nobody would be required to include such provisions in an end-of-life plan. But it would relieve the carers of some of the moral and legal load when treating those who do.

It is inconceivable that in the contemporary world people who are still cognitively able cannot determine when to end their lives should they eventually succumb to Dementia, or like illnesses in their many forms.

Any person should be able to prepare an end-of-life plan that dictates that when, for example, their diagnosed dementia gets them to the point where they cannot control their bodily functions, they do not recognise family, they cannot bathe themselves, get out of bed by themselves, or out of a chair. When they cannot verbalise anything much – or when they can't eat - why should they be required to continue with that 'life' because their heart is beating – until it stops naturally?

There is no magic treatment to reverse the collection of symptoms we call dementia, or stop it, or even effectively delay its progress. There is nothing to help people like me, who relate to the dignity and quality of life, from ending that life when it offers neither.

In my case, it's my life and I should have an option when to end it.

I am not proposing it be compulsory – people who for whatever reason choose not to exercise the option have every right to do so. But they have no right to tell me that I cannot.

My experience.

My experience is shared by many. Nothing here is unique. But that doe not make it less traumatic to see your wife of 51 years turn slowly from a dignified and thriving individual into one incapable of the simplest functions – not cognitive, not physical.

My wife Claudette was a linguist: she spoke three languages fluently and 2 others reasonably. She was active in the arts and an intellectually alive, dignified person.

To her dignity was an essential characteristic of life. Quality of life was important. She would say sanctity of life – professed by some – is ok for them but not for her. Yet she lost all dignity, all quality, in her final years.

We may well have a learned debate about unbearable suffering – and how to define it. My view is that she suffered even though she had lost the ability to articulate it. And losing that ability should not determine life's outcome.

It had to take its 'natural' course until an end – an end determined by people who profess compassion but do not put it into practice.

About 5 years ago she was diagnosed with dementia. She was 70 years of age.

It progressed slowly at first. We as a family adjusted to what started as quirkiness but got more difficult. We worked around it.

The progression was obvious in all the predictable ways. I could not manage even getting her to shower. She took up a room in a nursing home. The carers who looked after her extremely well – with patience, care and compassionate concern. I could not have asked for better.

She went downhill – as expected. She did not recognize me, her daughters or her friends. She had breast cancer surgery and radiation – which she handled well, in part, I suggest, because she was not aware of what was happening. She got to a point where she 'vocalised.' In other words she made sounds at a high volume to the distress of her neighbours in the nursing home – non-stop and loud. She was fed in her room.

About 18 months or so before she died she could use only one or tother of four words 'oui', 'non', 'yes', 'no'. She had lost control of bodily functions; she had difficulty eating.

For the last year she barely moved when I was with her. The carers in her nursing home needed a hoist to get her out of bed, in and out of a chair. I'm not sure how she washed, but it would have been very difficult. She would have been mortified were she able to see herself.

She rarely used even the four words. She was impassive. She had lost everything that was dear to her – her languages, her books, her family, her dignity, her quality of life. But her heart was still beating so it was OK – according to some.

Her last days were terrible. She was writhing in her bed, eyes closed and moaning. Her pain was treated by her carers.

She would not have conceded that the decline into indignity was acceptable had she known what was in store. Nor would she have missed an opportunity when cognitively aware to plan a dignified end-of-life on the chance that she may have developed dementia – her father had a bad ending due to Alzheimer's. She did not have that option. I do not have that option. Nobody has that option. Why?

I understand that there are those who preach the sanctity of life and argue with those who emphasise the quality of life, or human dignity. I am happy if that makes them happy.

They might have religion, I do not. They might be philosophers, I am not. They might be Psychologists (amateur and professional), I am not. They might wish to prolong their own life to the last possible moment regardless of some incurable, utterly debilitating, dignity-destroying illness. I do not.

Like them, I am presently cognitively functioning, and having experienced first-hand what dementia can turn you into; whatever the 'theory' I deny them the right to tell me when and how, or if, my life can be ended if I develop conditions that take away my capacity to decide 'on the day.'

I do not concede to anybody the right to tell me that their view is more important, or more relevant, to me than my own; to stop me exercising my right because of some construction they put on 'life' that I do not.

Yes, I have heard the stories about the heirs and successors and the greed. Yes, I know there would have to be safeguards, particularly at the point where the actions are to be triggered.

It is surely not beyond our wit to devise policies that secure the individual and also their wishes.

Just allow the option to those who want it.

I would be happy to discuss with the committee.