



**LEGISLATIVE ASSEMBLY
FOR THE AUSTRALIAN CAPITAL TERRITORY**

SELECT COMMITTEE ON END OF LIFE CHOICES IN THE ACT

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Submission Cover Sheet

End of Life Choices in the ACT

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From: Helen Crain-Welsby
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- I am 66 years old an Australian citizen who migrated and settled in Canberra in 1978. I have no political affiliation and I do not wish to be a strident voice in this debate, but rather to offer my experience and implore you to refrain from passing legislation which could lead to legalised euthanasia in the A.C.T. This is the first submission I have ever written. I have taught secondary and tertiary students for most of my working life. Again and again in my Ethics classes I read and heard their overwhelmingly well-reasoned arguments and their concern about this issue. I do not wish to be a polarizing voice in the debate Rather, I offer my experiences as a teacher who encouraged critical thinking, as an adult daughter who watched both of my parents experience loving and effective palliative care and die with personal dignity in the normal course of their lives.

Our Positive experiences with palliative care included very effective pain management combined with continuous physical and psychological support for my parents and for me and my immediate family from the beautiful people who supported them in a residential nursing home. They had their moments of darkness and fear but they knew and understood that they were not a burden. The pharmaceutical care was fully explained to us all and it did its job in my mother's final months of life. When she first went into the nursing home, she was fearful and wishing that she could die, but as she saw how genuine these (largely underpaid) dedicated people were, she grew more peaceful and expressed her appreciation that she had lived to see her grandchildren as adults. My father's experience at the outset was one of great fear until he went into care, struggling with emphysema/chronic obstructive pulmonary disease. He was visited regularly by a wise and unobtrusive pastoral care team in addition to the selfless physical and emotional support he received. I cherished the time that I could spend with my parents, seeing them happy to spend whatever time they had left with loved ones. My dad died in 1999 and my mother in 2004 and I still keep in regular touch with the nurses, the carers and the social worker who helped to give such meaning to these struggling and frail folks who moved from despair to hope. My dad, struggling to take his final breaths (I was with him when he died) said as one of his last sentences, "I'll never see that little nurses again (one of the pastoral and palliative care nurses) again." His final moments were very much his own autonomous experience and he was glad that he had "gone the distance" instead of giving up, giving in and pretending that he could ask for a happy death. My students understood the ethical principle of "double effect," whereby an increase in pain medication might in fact hasten death but that it was given in the spirit of dignified palliative care, not a wish to just go for the quickest option. One of my students said that she thought it was especially important that very ill people knew that we didn't just want to get rid of them but that we would take the time to actually BE with them as they walked the last journey.

It is SO important that the right medications can be found and that we put our money and our efforts into developing those. We saw one of our staff members/teachers in her last days at Clare Holland House and although she could no longer speak, she smiled to see us. Her family said that she had received excellent care all the way through and especially in those end days.

In America, I had worked as a "Hospice Caring" volunteer. This organisation had no government funding and was not aligned with any religious organisation. The nurses who trained me had worked with many dying patients and helped us to see that this volunteer work was one of the best things we could do. I worked with elderly clients (one had served in WWII) and one was in her 40's and repeatedly said how grateful she was that she could tidy up a whole lot of things at the end because the doctors and the nurses had been able to prescribe such effective medications. These trainers and these clients all helped me to reflect on the value of every life, right up to the final moments. Hospice is SO good and so affirming. It makes our lives seem so valuable, rather than something that can be cut short.

Look at Stephen Hawking! Some people might say that his life wasn't worth living when he got to a certain stage of MND--and yet look what he gave the world and the world can be so grateful for his bravery and for what technology was able to do to give his life meaning.

And how about [REDACTED] the 50-year-old who died recently after becoming a quadriplegic in a motorcycle accident at age 21. The Canberra Raiders football team was at his funeral. [REDACTED] devoted parents, who had done so very much to give him the best possible quality of life, said at his funeral, "He had a good life, after all." So very many people cared about and for him--it helped us to better respond to the challenges of being human.

My absolute hero in Canberra is my former breast surgeon, Dr [REDACTED] who died with more dignity than anyone I have ever known, I suppose I could say, letting nature take it's course. He was loved and he knew that and he accepted his illness and made the most of every day and every relationship that he had in his too-short life.

My [REDACTED] lives with schizophrenia and at one point early in the illness wanted to die. We love him so much and want to give him all the support we can as he has turned his life around and became a volunteer mental illness educator for the ACT. His life is as full as it can be and he is glad to be living it. We have been so grateful for the help he has received from wonderful people at ACT Mental Health and we are grateful for the support he receives from the NDIS to help him realise his potential and contribute to society.

We have wonderful people with so much goodwill in this Australian nation and our local community. Please, please, let them do their work and help everyone to feel valued as human beings until the term of their natural life is over. Consider first what we can do to share and support our common humanity instead of just cutting life off and pretending that we are giving people their dignity.

Thank you.

Helen Crain-Welsby

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