



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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To Whom It May Concern

I would like to tell you about the gift which was presented to me 8 years ago which I had the choice to reject or accept. That gift was to care for my elderly mother who had dementia until she passed away. I am an only daughter and the youngest of four children. I am married myself and my youngest son who was 6 years old at this time has special needs himself as he had been born severely prematurely at 24 weeks. This decision was not one to be taken lightly but as I said, this was a gift. When we are presented with a gift we have to unwrap it before we can truly see the beauty of it.

I had a difficult relationship with my Mum when I was young. My family was dysfunctional largely as a result of two very strong female personalities clashing with each other and also because my father suffered PTSD as a WWII Veteran from PNG. Add to that 3 young men who were also bursting at the seams and you start to build a picture. My parents' marriage broke down when I was 14 and I largely decided there and then that the sooner I could grow up and get away the better. I judged my Mum a lot because she was a very "highly strung" woman. Ironically, when my life started to unravel at 21 when I had a breakdown, it was she who understood my feelings of total aloneness etc. This was something I always remembered.

When Mum came to live with us, she had so many issues it would take all night to detail them here. Many resulted from the dementia and the inability to let people help her until she had no other option. At first it was a huge adjustment for the family and Mum. The first 6 months were particularly interesting in family dynamics and challenges but also very rewarding. We also have 4 children who, for the first time had a grandparent not only living close by, but living with them. The tyranny of distance had prevented this until we had to move Mum to live with us. During the next 5 years we would have many moments of laughter when Mum would do or say something which was totally without the normal barriers we put up to protect ourselves. She brought her own sense of self and added another rich dimension to our lives and the lives of our children even with her illness. She adored our disabled son in his simplicity and would look forward to a kiss goodnight from him every night. During this time there were many moments of reconciliation for her and myself. I have never forgotten her gratitude for me doing my best to look after her. One night as I was tucking her in after a particularly busy day, she said to me, "Steph I'm not afraid to die now.". I said to her, "Why not Mum?" and her reply was "because I know I won't be alone". This was to be so true as I was sitting with her and beside her when she took her last breath which was very peaceful. It is hard to sit beside someone when they are dying and naturally, when we love them we want to help them die as painlessly as possible. From my experience we can do this without intervening to the point where we take away what may be a very healing and spiritual experience for both the dying and the bereaved. Today we want to avoid suffering at all costs and believe that we are being kind to all parties involved. During the time I was with my Mum, although it was often difficult, when Mum passed I knew that both she and I had travelled a passage of life and death together. I will always be grateful my faith as a practising Christian gave me the courage to follow. I must state from the

outset that I do not like pain, I am not into self affliction and often in the situations life has presented me with, I would rather have been at the beach. That would have cheated me of the long lasting experience of loving until the end and having the opportunity to accompany my Mum on her journey to eternal life.

As Mum's illness progressed it became physically and mentally difficult for me to continue to care for Mum in our home and look after the needs of the rest of the family. I tried to get more permanent long term paid help in our home but could not acquire anything suitable so eventually I had to seek a place in a nursing home. Mum was only in the Nursing Home for 6 weeks before she had a bad fall and broke her leg. This situation became one of the most traumatic I have ever experienced, simply because good medical care could have made a huge difference to the final outcome. Caring medical care, could have relieved a lot of unnecessary pain and common sense could also have made a difference. Mum did not have that severe break operated on for 6 days while the Canberra Hospital and staff argued over how to organise surgery for Mum. She had a hospital acquired antibiotic resistance which she had acquired from Canberra Hospital on a previous visit. By the time Mum received her surgery etc it had taken a huge toll on her and myself, fighting for her rights. As a result, Mum also had a stroke and other complications occurred as a result of being bed ridden etc.

Mum did manage to be well enough to be transported back to the Nursing Home. There we celebrated her 90th birthday with her favourite, prawns, mayonnaise and some lemon, mashed so that she could swallow it. Even though she could no longer talk, she could still signal when she was enjoying something and that day she did. So did all my brothers and I, who were all together with her. Our childrens' lives were enriched by the fact that they could see the old, frail and ill, were still valued members of our family and society. My daughter recently helped care for her other Grandma who was very impressed that Catherine could get her hands 'dirty' and was not afraid of and actually really enjoyed her company.

When Mum began to die as a result of not only the stroke and the broken leg but also she developed a bed sore which refused to heal and acquired an ecoli infection, it was drawn out over some months. The ecoli infection was probably the worst and everybody was saying there was no way she would recover from it. She did. It was the damn bed sore that was the final straw and her body just gave out. It took 3 days for her to pass away and during that time we were always with her, making sure that she had enough pain relief to keep her comfortable but not making her unaware of us being with her. When our son returned from the 100 year recognition of the Australian campaign at Gallipolli, she was already unconscious but when he started speaking to her about his trip, her eyelids were fluttering in recognition etc and of the fact that she was hearing him. It was very comforting for me to have the experienced palliative care nurses visiting to assure me that medically speaking there was nothing else I could do to help Mum apart from making her death as comfortable and pain free as possible. They helped me to understand everything that was happening and that Mum was peaceful. As I had done for the last 5 years I told Mum I loved her and stayed with her.

On the afternoon that Mum died, I had just gone to get something to eat and prayed that she wouldn't die in the 10 minutes it took to get some food. I had asked for her to be changed previously and the staff had come to the conclusion it was probably neither her nor there at this point but if it made me feel that we were still caring for Mum as much as possible then it would be done. I was helping to put a pillow under her arm and speaking to her and reminding her that we were all grateful for her love and care of us when she so gently took her last breath, I didn't notice. Having had four children myself, it felt like the other end of giving birth. We struggle and struggle in labour and then the child arrives, new life. At the other end of life, towards death, once again, we struggle and struggle, and then we are born to a new and eternal life.

I realised from this personal experience of being beside someone dying, how important it is for all of us as humans, to enter and embrace this moment asking for the courage to stay the course to the end. The reason we all run from death today is because we try to deny its very existence in our everyday living and yet by doing this, we are ignoring an intrinsic aspect of our humanity.

My Mum and I had many moments of frustration and reconciliation during these five years. I am grateful I was given the opportunity to help her really, die with dignity, not being the one to decide when she should die but rather allowing nature and God to know when the time was right. Accompanying her on her journey and assisting the natural process to take its course.

Kind regards

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PS I also have the story of our 14 year old son who was born at 24 weeks gestation. We were offered euthanasia for him 3 times when he was fighting his prematurity. He has just been asked to play competition table tennis in a national competition in May. He plays soccer, dances, loves a joke and has cerebral palsy an intellectual disability, is partially deaf etc. He also is a gift. We don't control life and we deprive ourselves of joy and enrichment when we try to.