

Inquiry Name: Inquiry into End of Life Choices

Lea Thorpe

I want to die when I feel I cannot go on any longer. This is my dream.

Currently one's life is in the hands of others. My Mum is a case in point. She was in an excellent aged care hostel where she was much loved by staff. Mum had a lot of support from her children and friends. It was a perfect place for her as she was not able to live independently anymore. She had five very happy years there. The last twelve months of my mother's life was unhappy, painful, undignified, traumatic and stressful.

Mum:

- could not converse anymore after being a great talker. She was the “star” of the hostel, she knew everyone and had relationships with many people. She changed and could barely speak or respond to questions
- was frightened to stay in her room and would ring family crying and begging us to come up and stay with her. We would sleep in a chair in her room to assuage her anxiety
- sat in the foyer of the hostel and didn't use her room (and when she did, the door had to be open wide)
- had to wear large pads as she was incontinent. She was dependent on nurses to come when called when she had to use her bowels. Mum couldn't wipe her bottom and had to have help (from staff and family) which under normal circumstances she would have been mortified
- could not eat normally and although food was blended for her, she ate little and lost 20 kilos and continued to lose weight
- was on a concoction of drugs and no doctor, aged care specialist, pain specialist or pharmacist could tell us how they interacted or affected Mum's cognitive and physical functioning

Mum was clearly deteriorating and things came to a head when she knocked her leg and a huge hematoma resulted. She was taken to hospital and went into theatre to have the hematoma drained. This was not successful and Mum returned to theatre for another operation. Mum was unable to speak, eat or toilet herself. The nursing staff were very understanding but it was clear Mum was nearing the end of her life. I was assured that they were very mindful of her comfort and administered morphine when it was clear she was in pain.

Another specialist visited Mum and suggested she go back into theatre and he would do a skin graft. I was appalled and invited him to look carefully at my Mother and tell me if he still thought it was a good idea for her to have more surgery. He

apologised. Our dear Mother died that night. I didn't cry, I was so relieved and happy for her. The last twelve months were so undignified and unhappy.

Mum didn't want to die like this. We knew she wanted to die. She had written her wishes but alas, a dignified death was her dream but it was not to be a reality.

I have MS, my partner has secondary breast cancer, dying with dignity is a priority for us both. Please let that happen.

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