

Submission to the Victorian Parliament Inquiry Into End of Life Choices

I watched as my elderly mother writhed in pain as she took her last breath this year. She endured an excruciatingly painful death as I sat by her bedside willing, with all of my being, for her suffering to end.

It was her wish to die with dignity and at a time and place of her choice. The law prohibits this from happening in the state of Victoria.

I sat at her bedside as dementia ravaged her body and denied her the capacity to move, eat, shower and toilet unassisted. Her contorted form was confined to a wheelchair, yet she was not always in intolerable pain. The dementia did progress to the point where pain was a burden that she was forced to endure.

Five days before her death, she lost the ability to swallow. The anguish in her frightened eyes will haunt me forever. Her death was inhumane. It was cruel. Her body took five days to shut down. She lay in her bed and recoiled each time she was touched. She moved her head from side to side as if she was seeking a means of finding relief. Her limbs appeared to spasm as she screamed in agony. This didn't happen once, it happened over and over again, night and day. The palliative care medication did not stop the pain.

I did not leave her bedside. I did not want her to die alone. I did not want her to suffer. I sponged out the thickening saliva in her mouth. I tried to put ointment on her drying lips. Nothing alleviated the torment she was enduring. Nothing. She could not even cry as her body withered away. My mum was drying out from the inside and suffered because of a cruel disease and because of the law.

No one wants to die. It is not about death, it is about suffering. From the moment the doctors confirmed my mum's diagnosis, it was inevitable that she was going to die from lewis body dementia. We did everything in our power to ensure her life, post-diagnosis, was as comfortable as possible. When she was no longer able to swallow, we could not do anything to afford her any peace.

Enacting legislation to allow any form of assisted death should focus on the needs of the dying, not the hypothetical fears of those who argue that it would be a "slippery slope" and that no "safeguard" would work. Too often we fail to recognise what is right because we continue to invoke a mindset that disproportionally magnifies the threat change presents. We need to recognise the threat now posed to each of us if the legislation is not passed.

It is about choice. It is about ending suffering. It is about the choice to end suffering.

I held my mum's hand and looked into her eyes five days after her last mouthful of water. I had to go to places I never thought I would have to go. I looked into her eyes and saw pain. I saw indescribable pain. I saw a woman who had suffered. Her paper thin skin was grey in colour. The whites of her eyes were completely yellow. I told her she had done her job and that she had done it well. I told her that we would be alright and that I had been in awe of her courage. She gasped for breath and her heart finally stopped after 5 days, 120 hours, 7200 minutes and 432000 seconds. Not one of them without pain. Not one.

Unfortunately, I fear that it will not be alright until a system, safeguarded by legislation, is implemented to alleviate suffering and offer people a choice. Morality dictates that we are allowed to choose assisted death. It is time to change the law. It is past time.