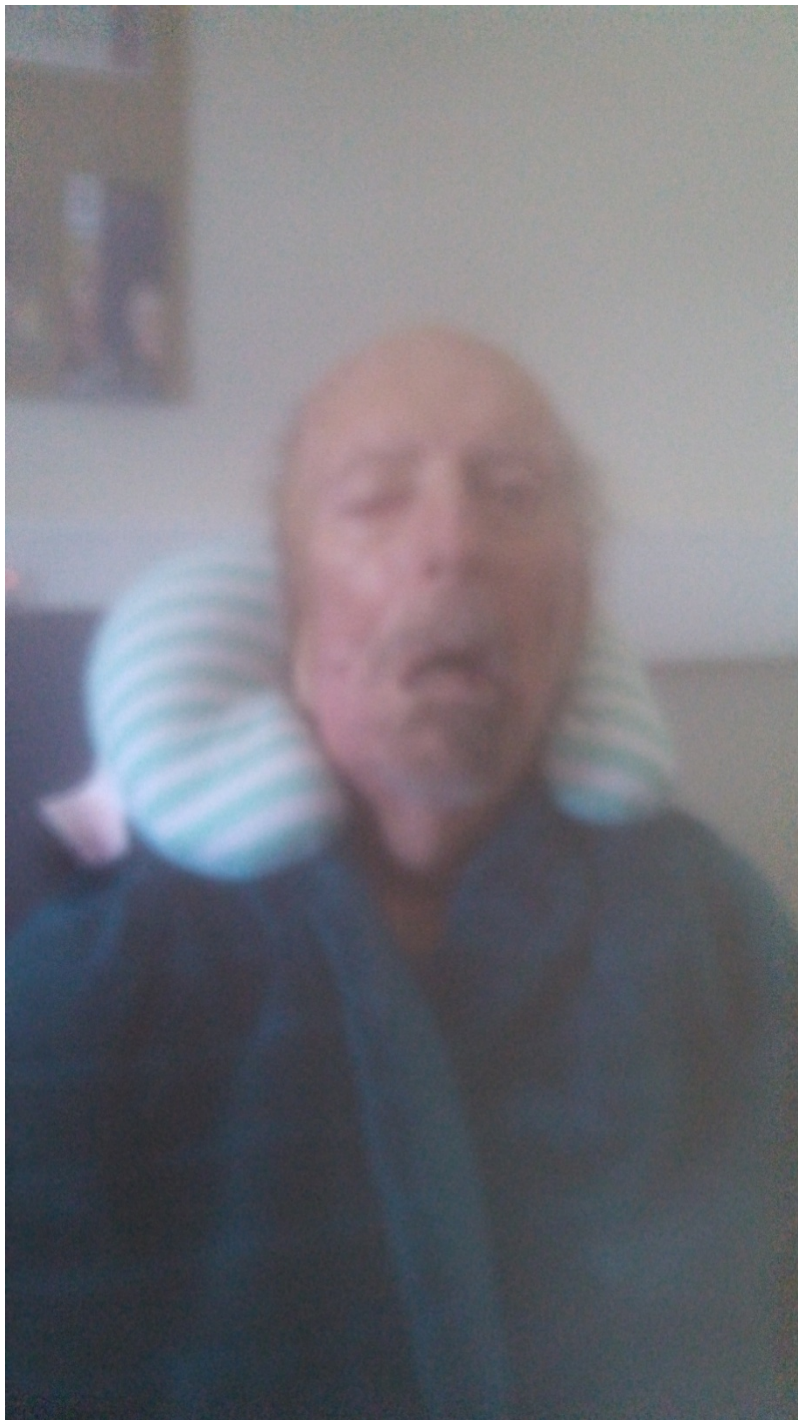


Legislative Council Standing Committee on Legal and Social Issues

INQUIRY INTO END OF LIFE CHOICES

Are Victorian Laws adequately meeting people's expectations regarding medical options available at the end of their life?

This photo of my father taken the day before he died on June 6th 2015. I apologise for the poor quality, it was taken on my mobile phone through a damaged lens.



Devastatingly, my father only had one end of life choice – to withhold all sustenance and liquid to hasten the terrible pain, suffering and indignity that his life had become. My incredibly stoic father had suffered for many years from squamous cell carcinoma breaking out in many parts of his body but particularly his head and neck area for which he required many invasive operations. In May last year he underwent a 19 hour operation to remove his right ear, ear canal and jawbone joint and resulting massive skin [with attached muscle] graft to cover up where his ear had been.

Unfortunately the doctors cut nerves as well which resulted in his whole right side of his face collapsing. He was not able to close his eye or mouth, breathe through his nostril or eat properly and was soon on liquids because of this. He also suffered terrible nerve damage pain and the cut nerves also affected his vocal chords and speech which caused him even greater frustration. He endured two more operations to try and correct his eye and tighten slings that had been placed in his cheek to try to pull his mouth up, neither of which worked.

His eye was constantly sore, red and weeping, he needed a clip to hold his nostril open to try to breathe while sleeping, though from being an excellent sleeper this was always compromised. Dad resorted to sleeping pills for the first time in his life which didn't really help much and caused constipation which he had never suffered from and needed medication for.

He constantly dribbled and had to tilt his head to even drink through the straw. As the cancer advanced into his throat he couldn't even keep his liquids down as the valve in his oesophagus was no longer functioning and it was going into his trachea causing vomiting and extreme coughing. Dad lost more than 20 kgs over a few months.

I actually feel I lost my true father after this operation because he had lost his dignity, his humour and his quality and lust for life although he never complained about his pain until the last week of his life. This was a result of being punished by his cruel father if he expressed pain in his childhood. He didn't laugh at all after this operation and I only remember one small smile in all that time when he blitzed my sister and I at Scrabble. He would have been in unbearable pain but because of his uncomplaining nature it he was not honest about it until even he could not cover it anymore. He was finally fitted with a morphine driver on the Monday before his death but it was not strong enough and after a few terrible sleepless nights he was forced to go to hospital to manage the extreme pain breakthroughs.

The palliative nurses from Calvary Care were very good to Dad and our family but it was really just a Bandaid solution to his end of life care & wishes. Dad wanted to die at home but realised his pain was unmanageable. We as his family would have loved this also, if he could have been euthanised with us around him would have been so much more preferable than him being totally overdosed on morphine combined with the fact he had decided not to drink anymore to try to hasten his demise. He didn't know where he was or why, it was scary to see this beautiful man totally out of control. He was very agitated because his stomach had bloated and was causing him to think he needed to empty his bladder but of course there was nothing there. He was constantly trying to get out of bed to go to the toilet which made for two very restless nights for mum and him. He was fitted with a catheter around 2pm on the day he died and almost immediately fell into a deep sleep from which he never woke.

Dad had all his family around him except for two grand-daughters, on the Friday afternoon before he died. After his grand-daughter read out a lovely card to him he forced out a whispered "I want to die" If not at home, this would have been a better time - if only he could have been euthanised with all of us around him it would have been a much better death. We were told his heart could go on for another week but on reflection this was fanciful since he had not received any sustenance or even any fluids for a week and the morphine had been increased to 50 mg. Under this false assumption only my mother & sister were at the hospital at this time, myself and another sister had gone home. Only my sister was in the room with him, mum was in the family room and this caused great bitterness for mum that she wasn't with him at the end. Most Australians wish for a dignified peaceful death surrounded by their loved ones. We don't let animals suffer in this way so why do we let humans?