

TRANSCRIPT

STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

Inquiry into end-of-life choices

Traralgon — 9 September 2015

Members

Mr Edward O'Donohue — Chair

Mr Daniel Mulino

Ms Nina Springle — Deputy Chair

Ms Fiona Patten

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Witness

Ms Terri Eskdale.

The CHAIR — Welcome. Thank you very much for joining us. I again declare open the Legislative Council's Legal and Social Issues Committee public hearing in relation to the inquiry into end-of-life choices. I would like to welcome Ms Terri Eskdale, who is appearing in a private capacity. Thank you very much for making yourself available.

Just before we start I caution that all evidence taken at this hearing is protected by parliamentary privilege as provided by the Constitution Act 1975 and further subject to the provisions of the Legislative Council standing orders. Therefore you are protected against any action for what you say here today, but any comments made outside the hearing are not afforded such privilege. Today's evidence is being recorded. You will be provided with a proof version of the transcript within the next week, and transcripts will ultimately be made public and posted on the committee's website. We have allowed half an hour for our session this afternoon, so I invite you to make some opening remarks and thereafter the committee will have questions.

Ms ESKDALE — Thank you for hearing me. I am going to begin with a short explanation of what it is like to live with multiple sclerosis. I am using submission number 3 in the submissions, from Lawrie Daniel, because he has made a really eloquent submission and a great explanation of what it is like to be living with a chronic illness.

These are his words:

I have multiple sclerosis. I have just turned 50 and have 17 years before I even reach retirement age. My MS has become rapidly progressive and has gradually stripped me of everything that made up my identity as an autonomous human being; my job, my roles as husband and father, my ability to contribute to others, my drivers licence, my ability to enjoy myself, my dignity. Just when you think things can't get any worse the disease takes something else from you, or gives you something you would never want to have to live with in your worst nightmares.

I divide my time between an electric wheelchair and an electric bed, and pain, fatigue and continence issues make me essentially housebound.

Even if I could adapt to those circumstances, you might think that a person could still find things to occupy their time that may make them feel that they have a reasonable quality of life. But pain and fatigue are my constant companions. When I say fatigue, I am not talking about the sort of tiredness I used to get after a hard day's work. I am talking about a bone-crushing weariness, total exhaustion, so that all you can do is lie there, staring at the ceiling for days on end, or just sleeping when you don't want to. When I am talking about pain, I am talking about acute pain, a searing agony that renders you unable to move —

Sorry, this is just such a good description.

The CHAIR — Take your time: there is no rush.

Ms ESKDALE — I will continue:

and groaning and panting with the terror of it. I am talking about chronic pain that is a dull, endless misery that is there when you go to sleep and there when you wake up, and which disturbs your sleep, and stops you getting to sleep when you want to. I'm talking about pain that we are all familiar with, and I am talking about pain that most of us will hopefully never experience — neuropathic pain. Neuropathic pain is nerve pain that arises in the peripheral or central nervous system. It can be like electric shocks, like a bruise that never goes away, burning, tingling, numbness, sharp stabs, or the feeling of a billion ants crawling through your skin and muscles, and it never stops, even for one second. I have uncontrollable spasms, tremor, seizures that wrack my body, render me unable to move until the spasms are over, and cause the agonising sensation of cramp, and afterwards, a bruised and washed out feeling. Any attempt to try and do any exercise is 'punished' by a crash that leaves me bedbound. Even brushing my teeth and eating is exhausting. I avoid showering because I just dread the pain and fatigue of it. I am heat and cold intolerant. I never wake up refreshed. I mostly wake up thinking 'Oh no, another day'.

Let me tell you that there are some things that are worse than death.

If I get worse than this I can expect to lose total control of my bladder and bowels, total control of my ability to move my muscles, the ability to toilet or bathe myself, my ability to eat, and my cognition may go and I may lose the capacity to speak properly. I may lose my eyesight. I may become 'locked in'.

My pain is not controlled. There is little or nothing that can be done for nerve pain and the drugs they offer you for spasms and pain are often worse than the disease, with a long list of horrific side effects. I may live in this hellish way for decades. Would you look forward to ever-increasing doses of 'pain relief' for decades, which slowly wreaks havoc on your body and mind? Perhaps at sufficiently high doses there may be a modicum of pain relief, but I imagine that at a dose that actually gives me relief I would be essentially comatose, parked somewhere, drooling.

Thank you, Lawrie Daniel. That just says it all. Who here would want to live like this? MS is not necessarily a terminal illness. It is a criminal mastermind that holds you hostage and tortures you for decades on end. Mark

could have lived for another 5, 10 or 15 years trapped in a body that did not work and was wracked with uncontrollable pain. I live with the consequences of his choice every waking moment of every day, and sleep is no escape. My greatest regret is that I was not able to hold Mark's hand as he left this world. There was no goodbye. Please consider people like Mark and myself as you make your findings. His death was not an isolated case. More people will not die if dying with dignity laws are introduced. They are already dying. But people could have access to be able to choose how and when they die in peace and with their loved ones present. Thank you.

The CHAIR — Thank you very much, Terri, for what you have said.

Ms PATTEN — Thanks, Terri. I really appreciate that you also included that poem in your submission — —

Ms ESKDALE — Mark's last poem.

Ms PATTEN — Yes, it was very beautiful. Obviously I know where you stand. I am wondering in our deliberations about this and any recommendations that we might make, whether you have any thoughts about what sort of safeguards and regulations we would need to put around enabling someone like Mark to make that choice?

Ms ESKDALE — That is hard, because it has got to be with people's consent.

Ms PATTEN — That is right.

Ms ESKDALE — Mark made a living will. He left a piece of paper in front of him saying, 'Do not resuscitate', and the ambulance people still tried to resuscitate him. But people have to take these measures before they are locked in and before they cannot respond.

Ms PATTEN — If we were to consider some form of voluntary euthanasia or physician-assisted dying, how would we ensure that it was safe? I am sure you have read some of the submissions about people concerned about a slippery slope or concerned that it might not be some people's choice.

Ms ESKDALE — It would have to come from the person themselves. I have a history of early-onset Alzheimer's in my family, and I know my father would not have wanted to be in the state he was in, so he would have had to make some kind of living will or make some kind of agreement with his doctor for once he got too bad. You would have to go before you had to. I do not know; you would have to have agreement from the person.

Ms PATTEN — Can I just explore that a bit further. In Mark's situation, apart from the MS, as a perfect end how do you think that could have happened? Do you think Mark would have been able to speak to a doctor? Tell me how you think it would have looked.

Ms ESKDALE — Mark had been in the care of the same GP for probably about 12 years. Mark's GP knew he was a voluntary euthanasia advocate. He had always planned to not live forever in a body that did not work. He had an incredible fear of being stuck in a nursing home. He did not want to get to the stage Lawrie describes — trapped in a body and they would keep him alive. They would have kept him alive for decades.

He had a good relationship with his GP. His GP always knew what Mark's intentions were at some stage. I always knew what Mark's intentions were at some stage. I did not know whether he would actually go through with it. It was a surprise but not a surprise. A long-term, longstanding relationship with a GP who knows your intentions and can help you along, and when you get to the point when you can no longer bear living, then perhaps the GP could come along, you could have family with you, and you could go peacefully, with dignity, without violent means and in a loving environment.

Ms SPRINGLE — On that theme, how do you think it would have been different in the immediate term around Mark's death if it had been legal?

Ms ESKDALE — If it had been legal, Mark, quite possibly, could still be alive. But he had gotten to a stage where he was having trouble using his hands, so he was at a stage where perhaps he would not be able to kill himself very soon. If he was able to legally end his life, he may be still alive. If he was able to legally end his life, he could have spent time with his children. He could have spent time with me. I could have been with him.

I could have held his hand as he left. Who wants to die alone? I was with my father as he died, and I just see it as a great privilege. It is a great privilege to be with someone when they are giving birth. It is a great privilege to be with someone as they are leaving the world. If I could have been there, I could have told him I loved him.

Ms PATTEN — Terri, thank you so much for sharing all of this. I just have one more question about the circumstances after Mark's death with the police.

Ms ESKDALE — Yes.

Ms PATTEN — We have heard of similar situations. In your case I understand it took a long time for the coroner's report to be handed down. Did you ever feel at risk during that time that somehow you would be seen as being guilty?

Ms ESKDALE — In a way I was lucky. Because we live on Raymond Island and there is a ferry service — lucky — I went off to the market. Mark said he would not go because it was going to be a hot day, and he did not want to be out in the heat. I said, 'I'll go, I'll pop over, I'll get some fruit and vegies and I'll come straight back', so there were people who saw me go to the market. There were people who saw me at the market. The ferry driver saw me go and come back. They knew that I was not there.

The police were very good. They were wonderful, but there were weeks and weeks where I just did not know whether I was going to be implicated. I had fears that there might be a problem. Mark left a note, and he said things in his note like, 'This is why I had to do it without your assistance', so he was leaving messages. I am sure he was leaving messages for the police really, not me, but yes, there were times when I worried. That is why he did it when I was not there, because he was protecting me. You see it on the news. People get arrested. If I had been there, I would not have stopped him.

Ms PATTEN — Thank you.

The CHAIR — Thank you, Terri, for sharing your deeply personal story with us. It takes great courage to do that, so we thank you very much for being with us today.

Ms ESKDALE — Thank you for hearing me. Thank you.

The CHAIR — I said at the introduction you will receive a draft of the transcript by next week, and ultimately the transcript of today's hearing will be made public.

Ms ESKDALE — Thank you.

The CHAIR — Thank you very much.

Ms ESKDALE — Thank you, everybody.

Witness withdrew.