

SUBMISSION TO
VICTORIAN PARLIAMENT
STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

INQUIRY INTO END OF LIFE CHOICES

Submission by Terri Eskdale

My submission is intended, by personal experience, to show the harm done to individuals as a result of current laws affecting end of life choices. I'll try not to be too long winded, but I would really like the Committee to share my experiences.

My life partner, Mark Brennan, was born in 1948, and ended his own life on 9th February 2014.

It was our current laws that dictated that he took his life and what happened after.

Mark was born in 1948 in Great Britain and moved here with his family when he was 11 years of age so his father could take up a position at Sydney University. After training at the Sydney Conservatory on trumpet as a young teen with the prospect of a position in the Sydney Symphony Mark decided he wanted music to be a pleasure, not a career, and went to University to study law. He eventually turned to Teacher education, lecturing at Charles Sturt University in Wagga Wagga, He published books pertaining to linguistics and the law, he also ran courses in Judge Education, and was a pioneer in adult literacy courses.

In later years he gained a Doctorate in Education, of which he was very proud.

After a series of unfortunate accidents and illnesses over the course of some years Mark was diagnosed with Multiple Sclerosis and Ankylosing Spondylitis. It was decided that he was no longer able to work and his professional career was cut short. His marriage ended and he moved to the family holiday house on Raymond Island in the Gippsland Lakes. He set up a choir on the Island, this is where we met, after a few years our relationship began.

It was here that he set up his own small publishing business, Wind and Water Press. He wrote and published poetry and also edited and Published the works of others. As his ability to work complex tasks diminished, he turned to his more creative side and took up Bookbinding, making quality art books and journals for writers and artists. He also greatly enjoyed restoring old books, people would bring their most treasured family books for Mark to repair.

We sailed Mark's boat, a century old cuta boat called Meeka 2, and enjoyed playing music together at first as a duo and then in a jazz band. We travelled to Sydney and brought a new bigger boat that we restored and renamed Sea Creature. It was the boat of Marks dreams and we had many wonderful adventures in her, sailing often in the Lakes and also out into Bass Strait with others on board.

Our relationship grew and eventually we moved in together (along with my two youngest children) despite Marks reluctance to take on another family especially with regard to his health.

As time went on Mark felt the boat had to go as we could no longer maintain her as well as she deserved. This was a heart breaking move but best for the boat.

He worked hard on maintaining a healthy mind and body. Slowly though, his body became more and more unmanageable and life became a game of adaptation and compromise.

I guess people who are not familiar with the intimacies of MS could think that its just about people whose legs don't work any more. MS is a mystery illness, it manifests differently for everyone. Mark's walking and balance were affected and the most obvious symptom. His feet and toes had no feeling, while he still could walk, he would go down the street to the boat in bare feet and not even notice he had taken chunks out of his skin on the rough gravel road. In contrast to his feet, his skin elsewhere became extremely sensitive making wearing clothes uncomfortable.

Mark experienced shooting pains through the left side of his body. He had spasms that often came at night. He had short sharp pains that would wake him in the night. Pains under the skin that he called snakes and spiders. He had bladder infections. He gradually became incontinent. His bowels stopped working and he relied on fierce medications which would suddenly send him exploding to the toilet, too bad if you were out and about! Some days his eyes were reluctant to focus.

Although he remained an intelligent man, contributing to his community right to the end, he found concentration would fade and he had to stop going to things like community meetings and he found writing difficult. Mark's legs would sometimes seize up and he would become stuck in the car, or out of it. Telephone calls became exhausting, we became isolated in a way but Mark made a point of going out and about in his mobility scooter every day to the village for coffee and bits and bobs. This was the most social part of his life in the last few years.

We were part of an MS support group and Mark was the most badly affected in the group, however he still made contributions to the group. He did a training course to be an MS peer support worker and did telephone counselling for people who either were newly diagnosed or were isolated in some way by their illness.

We both spent a week a number of years back at the Gawler institute with Professor George Jelinek who is an acclaimed medical professional specialising in MS who has himself got MS. He prescribes a strict diet which we both converted to. I did not manage to keep to it for long but Mark did. We had always eaten well anyway. Make gave up drinking alcohol for his health about 12 years before he died too, with great benefit.

Mark was well known and loved in our local community. He gave his time and care to many people in need.

By December 2013 he was assessed as high needs which meant if he was admitted to nursing care he would have been in the high care side of the nursing home, and they would have kept him alive against his wishes. The most devastating loss to him was when he began to lose the dexterity of his hands. He never complained about pain but experienced a lot. Towards the end he was unable to sleep in a bed due to the pain and spasms when he lay down. He slept in an electric recliner chair.

Mark was a person who enjoyed being busy, he was not one to sit in a chair watching films all day. As his disease progressed the fatigue he'd always experienced became worse and he couldn't work for more than half an hour at a time.

But his greatest fear was that he would get to a stage where he would not be able to end his life because his hands would not work.

Mark had always been an advocate for assisted dying, dying with dignity. It was not a rash or spontaneous act, rather the considered position of a highly intelligent person facing a disease that wouldn't let up.

If we had laws that allowed a system where people could choose to end their life on their own terms Mark may still be alive today.

Mark tried unsuccessfully to buy Nembutal from Mexico at a high cost. He suggested if he had it there he would feel comfortable to continue to live, in the knowledge that if it all became too much he would be able to relatively easily end his life.

Mark died alone and without a word of goodbye because he had to protect me.

That is what upsets me the most, he had to die alone and in an unnecessarily violent way.

This has affected me in many ways. People seem to think that now I am not a carer I am free to live a new life. I am not, I am mourning the loss of my life partner and I am dealing with the shock of finding him dead. I should have been able to be with him and hold his hand, it would have been a comfort to both of us.

In a perfect world Mark would not have had MS, in a better world Mark should have been allowed to live until he decided to end his life at a time that suited him in a comfortable way and surrounded by the people who loved him.

With Dying with Dignity laws in place Mark might still be alive.

With laws in place his death would not have been a shock for me, nor a source of gossip for the community.

The police would not have had to spend many hours at our house on the day he died.

His body would not have had to be transported to Melbourne for examination, delaying funeral plans.

Months, almost a year, would not have gone into a coroners report on his death, bringing a stream of reminders in the post every few months as I was kept up to date.

Mark's death certificate mentions only the cruel way he died, not that he had a crippling illness that forced his hand.

I thank you for reading to the end of my submission. I know it was long and personal, but I believe it is important to appreciate how current laws play out, and how we as a community could do much better.

I wish the Committee well with its considerations.

I am willing to attend the Hearing.

I have included below Mark's last poem.

Never Ending Poem

A single blanket of soft mist cradling
the sharp shape of a
greater crested grebe
the single shag
the single azure kingfisher
checking my attention
and with passing intent
the pardelot that just for a second
or two
lands on my shoulder
give rise to the
thought
that the time
to go is not when such moments have
run out but
whilst
they still exist.

Mark Brennan
January 2014

Terri Eskdale
1st July 2015