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**From:** Jane Morris [REDACTED]  
**Sent:** Tuesday, 28 July 2015 9:48 PM  
**To:** LSIC  
**Subject:** Submission, end of life issues  
**Attachments:** Euthanasia DWD.docx

To whom it may concern,

I wish to submit my personal story to The Legislative Council's Legal and Social Issues Committee. My story is one written from my own individual perspective. My mother's death was so recent that it has been impossible for the remaining immediate family to talk about her death as the vivid and shared memories are so raw and emotive.

Despite the fact that I have on numerous occasions referred to what 'we' as a family endured, I feel it necessary to emphasise that the views posited are strictly mine.

I would like to appear at a public hearing.

Thanking you for consideration of the attached letter

Jane Morris

## Euthanasia, DWD

A few years ago a dear friend died. His death was not totally unexpected. We all accepted that it was his time to leave this world. I sat with him as his doctor and nurse respectfully hastened his imminent death. Without intervention, the initial signs of stress and suffering he displayed would have only become exacerbated over the ensuing hours. My little friend fell asleep surrounded by love and compassion. I held him and gazed into his trusting eyes. His doctor later referred to him as 'the dearest of little gentlemen'. She and her nurse shed unbridled tears. They had grown to love him too. My friend had taught me much about love, loyalty and happiness. His last lesson was to show me that death can be beautiful and that shared grief a huge privilege.

Recently I was privy to another death. This death was cruel and tortuous. It has left an indelible mark on those of us present and the resultant torrid memories have become firmly entrenched within our minds scarring our lives forever. It was not a peaceful and gentle death but one devoid of dignity and compassion. It was an ugly death.

The former death, one which I am sure would be considered 'humane', and one I fervently believe we should all have the option of choosing when terminally ill, describes that of my little dog. I did not question the Veterinarian about her decision to end his suffering as I respected her professional judgement. Prolongation of his life was not even a consideration as it would have been cruel and heartless to have protracted his suffering.

The latter that paradoxically could be referred to as 'inhumane' describes the death of my beautiful, gentle and courageous mum. Her death was insufferable, the type of death which we all fervently hope to be spared. None of us can envisage the exact circumstances of our death. We all hope for a peaceful end to our lives but suffering in death is indiscriminate upon whom it inflicts.

Many people today document personal end of life care wishes. This documentation enables an individual who may develop a terminal condition in which they envisage life will become insufferable, to refuse treatment which would prolong an unendurable existence. Therefore in certain circumstances, providing appropriate documentation is available an individual has a right to refuse treatment. However a patient has no right at all to request treatment that may hasten imminent death and end their existential suffering.

I have always been, and never more so than at present, a vocal and extremely passionate advocate of the idea that the terminally ill should be allowed to die at a time of their own choosing. This autonomously derived decision should be respected by others irrespective of their own views. I have nursed the terminally ill and have gained further insight into the complexities of the whole 'Euthanasia' concept through further study. I have always expressed my views with clarity and conviction. I am now however at great pains to elucidate how it transpired that my own dear mother had to suffer the hellish nightmare that we had all fervently hoped was preventable.

Today in Victoria we are afforded many rights and privileges denied to many other individuals worldwide. We have the right to choose whom we marry and if we marry at all. In the last few decades we have been provided with a plethora of procreative rights which help us decide when, how and if we want to reproduce. We have the opportunity to transfer our religious allegiances and even the right to undergo gender reassignment. Why then are we so determined to silence the

voices of the dying and ignore their requests to make a last and final decision? When death is imminent, why do we not have the right to say how and when we want to die?

My mother was diagnosed with what is now commonly referred to as “the beast”, Motor Neurone Disease. The shock of the diagnosis was indescribable for us all. MND is a terminal disease, one in which the slightest hope for recovery is denied. It is not a disease which advances in typical progression. Every day was full of uncertainty every medical appointment frequented with the fearful expectation of worsening news. As we quickly learnt with MND it is futile to hope for positive news, there is never any.

From the point of diagnosis we worked frenetically to resource as much available information on all aspects of MND care. Throughout the duration of the disease we tried, albeit in veil, to miraculously chance upon a way to slow down the progression of the disease and try to avert it from its forever changing tortuous course. Mum’s decline was extremely rapid and within 2 months of diagnosis she was unable to talk. We all fear losing our sight or hearing but as we rapidly learnt the inability to speak is devastating. Unable to utilize modern technology, communication through written language was frustrating, tiring and onerous. Unlike a vocalized fleeting thought, permanence is attributed to written words. Consequently it became progressively more difficult for mum to express personal and intimate thoughts.

Before mum was deprived of her speech we had talked about dying, her expectations of death and the manner in which she would most probably die. She did not want to suffer and being the incredibly selfless person she was she did not want dad or us children to be privy to such a traumatic event. Naively with faith in a system I knew to be plagued with legal and ethical issues I felt reassured by medical staff that this scenario would not eventuate. Never for a moment did any of us envisage the horrors of MND to which she would succumb. Twice my parents were reassured that there would be no suffering at the end. In hindsight perhaps we should have asked to have had the concept of ‘suffering’ defined to us.

We were bombarded with information on MND. Every day was different and no matter how much we all tried to attend to her numerous needs, mum’s decline was relentless. Soon after losing her voice she struggled to swallow fluids and had a PEG tube inserted to ensure she remained hydrated especially over the oncoming summer months. It was not long before eating became extremely difficult. My beautiful mother who had always had the most refined manners had to be fed like a child. It was heartbreaking to watch her and we knew it was just as heart wrenching for her to know we could see her in this miserable state.

MND became a constant in our lives, every second of every day. It overtook mum and dad’s lives, ours and finally their beautiful home and garden could no longer provide refuge from this hideous and continually pervasive disease.

Mum would have the occasional week or two in palliative care for assessment and although we were reluctant to confess it provided some much needed respite for us all. The care in palliative care during these stays was exemplary. It is impossible to describe the dedication of all the staff. Their compassion was palpable and care admirable. Mum’s final return home proved challenging as her care became increasingly intensive. The special and quiet times we had previously shared with mum interspersed with moments of humour and happiness were no longer present. It would be

disrespectful to list the many, many indignities she suffered. The home help carers became like family and were some of the most beautiful people I have ever met. They loved mum and cared for her like she was their family. At no stage did we ever doubt that mum was being provided with the best possible care available.

Around this stage, mum managed to convey to us that she wished to die in hospital. Once again this incredibly selfless woman, who had given so much to everyone during her life, was again thinking of others and did not want to die at home where she knew dad would continue to live.

Mum's condition became unmanageable at home. She was in severe pain and afflicted with many other conditions as well as the MND now ravaging her body. She returned to palliative care and we dared to hope that she would return home unable to acknowledge the futility of our wishful thinking. Again we returned to the incredible nursing staff and placed our faith in a system in which we hoped would provide mum with the death devoid of suffering that she had been promised.

Upon her final admission mum was actively treated in palliative care for an unanticipated condition that had been left untreated would most probably have resulted in rapid death. Mum had previously stated to staff and family that she did not want to be resuscitated if she suffered a cardiac arrest and did not want to receive treatment for life threatening pneumonia. We did not explore the multitude of other possible causes of death. They would have been too numerous to have listed or even envisaged. It was by now evident that mum was dying. She was suffering physically and mentally. Everyone who loved her family, friends and many staff members had all become silent companions to her suffering.

Mum's last few days will be etched in our minds forever. Acknowledging that mum was dying, her plan of 'care' was changed. It was decided that as she was dying, she would no longer be fed or hydrated. She was however to be given analgesia to provide 'adequate' pain relief and her anxiety would be similarly controlled. Distressingly several times in the last few days she motioned to us. I will never forget the moment she held up her PEG tube motioning us to feed her. Mum also managed to convey when she was in pain and most distressingly was able to communicate that she was afraid. We had been assured that she would be unaware of her plight. Allowing this to occur is surely reprehensible. Some family members pleaded and pleaded that she be given extra pain relief to not just manage her pain but to hasten imminent death. Forgive me for equating this story back to that of my dog but I feel it necessary as it was at this stage that his death was hastened and he was 'put to sleep'. My request for similar management for mum was interpreted as a request to 'kill' and interpreted as a request to engage the medical staff in a criminal act. I found such emotive language extraordinary and extremely offensive. We did not want mum killed. All we desperately wanted was to see an end to her suffering.

I look back now in sheer bewilderment and amazement. How did mum ever end up at this stage? I can only say that from the moment of diagnosis it seemed as though we embarked on a treadmill on which it was impossible to step down from. In our eagerness to have the best nursing care, the best equipment, the best drugs, in fact the best of everything for her there did not seem to be a time where we could step back and try to objectively reflect on what was actually happening.

I have asked myself hundreds of times every day since her death, when would have been the right time for her to die. MND is often described as a disease in which the mind is trapped within a

helpless body. However, in some cases there are cognitive changes, some of which mum suffered from. With so little chance to communicate with her, it was hard to tell if mum was totally aware of her state and for her level of competence to be accurately assessed. During the latter stages of her illness she had indicated on occasions that she wanted to die. With little chance to adequately express her feelings such requests were often dismissed and attributed to her anxiety. Her anxiety would abate with the administration of medication and further 'talk' of death abandoned. It is now that I have time to ponder the question of the ethical nature of administering medication to address anxiety and depression in cases of terminal disease. Are we simply attempting to deny those individuals a request to die? I have reiterated on many occasions and will do so again but the inability to adequately communicate was the cruellest of assaults. We know that at times in her final days mum was in pain and afraid. However she did not have the chance to express her wishes about her end of life care. We could only reflect back and think what this once vibrant, gentle and forever loving person would have wanted. She would have been most distressed knowing that her suffering was causing so much torment to others.

Mum's time in palliative care taught me so much. I learnt so much about the resilience of the human spirit. As healthy individuals, we may conjure up an image of a scenario in which we would imagine life not worth living. However like so many times in life, the fear and anticipation of what may eventuate is often worse than the reality of the situation. Conversely a situation never contemplated by an individual may arise. They may deem this unforeseen state of affairs intolerable and as a competent individual request medical intervention to hasten imminent death.

Is it naive to believe that our medical system today has a patient's best interests at heart? Distressingly the approach to death and dying appears to be undermined by the fear of litigation and as a result contrary to a patient's best interests? Those that work in palliative care are compassionate and benevolent individuals yet they must work within litigious parameters and as a result patient care is compromised. Recent headlines have stated that medical professionals are uncomfortable giving pain relief to elderly patients! What has gone wrong with our medical system? First and foremost what is in the best interests of the individual patient should be irrefutably the primary objective of medical care.

Mum's death taught us all that death *is* something to fear. We were denied lasting memories of shared tenderness, love and togetherness. Instead those last intimate moments have left us scarred with the bitter memories of mum's suffering. Mum had suffered her battle with MND so courageously and totally devoid of self pity. At the end she deserved a peaceful death one of which could only be ensured with human intervention. Tragically this was denied and as a result her cruel and unnecessary suffering will plague our lives forever. My dear, dear beautiful mum spent her life looking after others. She never deserved to fall victim to MND and never ever deserved to fall victim to a medical system dominated by the fear of litigation. Until changes are made many more people will die suffering and leave behind relatives and loved ones traumatized and fearful of death. Any discussion involving the subject of Euthanasia is complex and highly emotive but this has been the case with many other extremely contentious social issues of our time. Because it is a topic that involves ethics, religion, politics, medicine and religion it is for many people, until they are affected, viewed as a minefield, one they find easier to avoid. Euthanasia is all about choice for the individual. As I have discussed it is difficult to pre-empt the conditions in which we envisage life will become

intolerable and it is just as difficult for loved ones caught up in an emotional rollercoaster to assess at what exact point in time intervention should be sought.

I emphatically believe that just as I accepted my Veterinarian's professional judgement that my dear little dog was suffering and the most compassionate and humane way to help him was to hasten his imminent death, the medical profession with great urgency needs to adopt such an approach to end of life issues. Medical professionals need to be convinced that helping a patient to die with dignity at the time of their own choosing is an act of compassion and care. Death is sometimes the only cure for interminable suffering and we all should have the right to be provided with this form of treatment if we so desire. Just as an individual's life lives on through family and friends so can the trauma of an inhumane and cruel death.