


Shayne Higson



To: STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES (LEGISLATION AND REFERENCES)
Inquiry into End of Life Choices
Parliament House, Spring St
EAST MELBOURNE VIC 3002

Inquiry into End Of Life Choices

Thank you for the opportunity to make this submission and I would be happy to appear at a public hearing, if requested to do so.

I will address the three terms of reference, however, the main point that I would like to make, based on the experience of my mother who died in 2012 from an aggressive brain cancer while under the care of one of Australia's top palliative care physicians, is that unless we legalise voluntary assisted dying, we will never be able to ensure that patients won't be forced to experience unbearable suffering at the end of their illness.

No matter what changes are proposed to palliative care or Advanced Health Care Directives (AHCD), if they do not include the legalisation of voluntary assisted dying, unacceptable, tragic deaths, like my mothers, will continue and the family members who are traumatised each year after witnessing such deaths, will continue to push for law reform.

Addressing the Terms of Reference

(1) Assess the practices currently being utilised within the medical community to assist a person to exercise their preferences for the way they want to manage their end of life, including the role of palliative care.

Some of the practices currently being utilised within the medical community, such as the use of AHCD's and giving a patient the right to refuse medical treatment, do assist a person exercise their preference at the end of their life and I am confident improvements will be suggested as a result of this inquiry. However, current practices do not allow for the

most important preference of all at the end of life, that is, the preference to die peacefully without suffering.

Under current medical practices the only legal option to hasten death is the practice of 'terminal sedation', in which a patient is administered a combination of a sedative such as Midazolam and pain medication, usually morphine, to render them unconscious as they slowly dehydrate and then die. This practice is sometimes used at the end stages of a terminal illness or when someone is experiencing unrelievable suffering. However, it does not always enable a dying individual to avoid suffering, as it is only applied after a doctor (not a nurse), witnesses what he or she considers to be 'unbearable suffering'.

The cruel death of my mother from brain cancer highlights the failings of current medical practices and has moved me to become an advocate for the legalisation of voluntary assisted dying.

Here is Jan's Story:

My mother, Jan Scott Ryder, was a beautiful woman who adored her partner, her three daughters and her five wonderful grandchildren. She loved her life.

In May 2012, aged 77, Mum was diagnosed with terminal brain cancer. Initially she spent 3 weeks in hospital and, with each visit from her doctors, the news got progressively worse. Mum had a very aggressive form of glioblastoma multiforme and with multiple tumours they did not want to operate, or do radiation therapy, for fear of causing severe brain damage. Before leaving hospital Mum asked her neurologist, if he would 'look after her in the end' and give her something 'before it gets ugly'. He, of course, could not make that promise and, in fact, she never saw him again as she was then referred to a Palliative Care Team.

Mum did not want to enter a Hospice and we were happy and able, to care for her at home. However, Mum always had the expectation that the doctors would not let her suffer in the end and that she would have a peaceful death. This is not what happened.

In the beginning Mum still managed to get some pleasure in life, even though she rarely left home. However, like many people with a terminal illness, Mum's quality of life deteriorated quickly.

Mum underwent a number of courses of chemotherapy hoping to extend her life a little but she always understood that there was no cure. As the months passed her physical condition and quality of life continued to deteriorate.

As the cancer progressed Mum lost her ability to walk, even with her frame. She lost her words and struggled to communicate. She was unable to write, unable to read, unable to talk on the phone and, towards the end, even listening to the radio or watching TV caused great discomfort. She was sleeping more and more each day and she had headaches and constant nausea. But even when Mum was bedridden and it took two people to carry her to the toilet, and she couldn't even wipe herself, she still wanted to live.

In early November the doctors decided to stop the chemotherapy, as it was doing nothing to improve Mum's quality of life. Each day Mum's condition worsened. We did everything we could to try to keep her comfortable. Every day I would rub her legs and feet because she said it felt like they were dying. The nausea medication did little to help her discomfort, apparently because it is the brain that creates the nausea, not the stomach. As Mum's right side became more and more affected she could not even lie in bed peacefully. It is hard to know what was so disturbing, but we constantly had to reassure her that she was lying in the centre of the bed. She was very agitated and distressed.

Mum started to ask for some form of medication that would just knock her out but nothing the doctors prescribed achieved a peaceful state. Each day it got worst. Mum had had enough. She kept asking, "Why are they doing this to me?" "Why are they torturing me?" When the Palliative Care Team visited on November 12th 2012 her ability to communicate was nearly gone and she struggled to get the words out but she did manage to get her message across. Tragically there was nothing they could do.

By 14th November Mum no longer wanted to eat and she had difficulty swallowing her medication. On the following day she asked me whether it would be over soon. Each day she asked, "When will it end?" "Just give me something to end it", but I couldn't. I was so afraid. No one tells you what to say or what to do in these situations. I knew the end was near but it was so hard to see my beautiful mother suffer like this. The doctors had been so dishonest. They had told her that in the end she would just sleep more and more and then just not wake up one day. I

know, in the end, if Mum had been able to end her own life she would have but by that stage she was like a rag doll. I felt like I had failed my Mum. I had promised her that I would be with her to the end and that I would not let her suffer. But that was just not possible.

By Tuesday 20th November Mum no longer smiled. On Wednesday morning she struggled to say, "Not another night," then later that day her final word - "finish". At that point Mum's G.P. suggested it was time for Mum to go to a Hospice. That was something our Mum and the whole family had never wanted but we felt we had no choice. The palliative care team had not been willing to provide 'terminal sedation' at home or certainly not at that point, despite Mum's pleas over the previous few weeks.

The next day Mum was taken to a Private Hospital and she was under the care of one of Sydney's top palliative care physicians. I am not sure if she even knew what was happening, she couldn't speak, she just stared. Fortunately the hospital allowed us to stay with Mum and we were so grateful for that but we still couldn't prevent a traumatic end.

Right at the beginning of Mum's illness she had suffered two seizures. The first was what led to her diagnosis and the second happened just days after she was originally discharged from hospital. Mum's greatest fear throughout her illness was that she would suffer another seizure. She had described it as like having a giant slamming back and forth inside your body but fortunately changes to her medication prevented this. That is, until the end.

By the time she was admitted to the Private Hospital Mum could no longer swallow, so she was unable to take the anti seizure medication. On that first night my worst nightmare came true and Mum suffered another seizure. It took nearly an hour and a half to get the seizure under control because the nursing staff were only authorised to administer a certain amount of Midazolam every 15 minutes. It was so traumatic to watch Mum suffer and I couldn't understand, and I still can't, why she wasn't given the chance to pass away peacefully in those final days.

I now realise that unless you can find a compassionate doctor and supportive nurses who are willing to effectively break the current law, a dying patient will be forced to endure horrendous suffering before the medical staff are willing to hasten

death using terminal sedation. In other words, you cannot request a peaceful death to avoid that suffering.

Mum suffered a seizure, pain and other distress over three days before she was eventually sedated to a level that at least masked those symptoms. She died 48 hours later but I will never forget the tortured expression on her face once she had taken her final breath.

How can we say we live in a humane society? Nothing could have stopped my mother's death from brain cancer but it would have been possible to provide a peaceful end, if only it was legal. Despite all that Mum had been through it was only in the last few weeks that she pleaded for someone to end her suffering. We all let her down and that is a burden I will carry for the rest of my life.

(2) Review the current framework of legislation, proposed legislation and other relevant reports and materials in other Australian states and territories and overseas jurisdictions.

I am confident that other submissions from organisations, such as Dying With Dignity, will provide examples of proposed legislation and other relevant reports. However, in response to this section, I would just like to say that based on the evidence from overseas jurisdictions in Europe and America, we know that voluntary assisted dying laws can work safely and effectively and there is no 'slippery slope'.

Some opponents of voluntary euthanasia argue that we should simply maintain the 'status quo' but I totally disagree. At present we have a situation in which a very small number of medical practitioners are willing to break the law and risk prosecution by providing medication that will allow their patients to die peacefully at a time of their choosing. Others are willing to break the law and risk prosecution by providing terminal sedation early in the process of dying, knowing that it will hasten death. But I believe the majority of medical practitioners in palliative care, while abiding by our current laws, will only provide terminal sedation as a last resort and only after a patient has endured horrendous suffering. This should no longer be tolerated. It should not be a lottery as to which type of doctor a dying patient gets. It makes no sense to turn a blind eye to compassionate doctors who are breaking the law and at the same time leave some patients at the mercy of other doctors who are unwilling, for legal or religious reasons, to grant the wish of a dying patient to die peacefully. The law needs to be changed.

(3) Consider what type of legislative change may be required, including an examination of any federal laws that may impact such legislation.

I trust that after hearing real stories such as my mother's, the committee will be able to recommend a bill that will include all the necessary safeguards but which will also make a voluntary assisted dying law workable, so that unnecessary and prolonged suffering can be avoided.

I think it is important that any proposed bill is clearly worded and I recommend that the committee look at the wording of previous bills, such as Tasmania's *Voluntary Assisted Dying Bill 2013* or the NSW *Rights of the Terminally Ill Bill 2013*. Both these bills were concise and included clear definitions at the beginning of terms that would be used throughout the bill.

In conclusion, I would like to propose the following key points:

- The current situation is inhumane and at times results in distress for both the dying patient and family members.
- Palliative care cannot prevent or even alleviate all suffering.
- Individuals facing a traumatic, painful, undignified or distressing death should have the right to choose a peaceful, medically assisted death at a time and place of their choosing.
- Voluntary assisted dying laws can work safely and effectively.
- Laws should reflect the values of society and the overwhelming majority of Australians want voluntary assisted dying to be legalised.

I sincerely hope that Victoria will lead the way and be the first Australian state to introduce a humane dying with dignity law, a law that cannot be overturned by our Federal Government as the Northern Territory's *Rights of the Terminally Ill Act 1995* was back in 1997.

Yours sincerely

Ms Shayne Higson