



LEGISLATIVE ASSEMBLY
FOR THE AUSTRALIAN CAPITAL TERRITORY

SELECT COMMITTEE ON END OF LIFE CHOICES IN THE ACT

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Submission Cover Sheet

End of Life Choices in the ACT

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Submission to Inquiry into End of Life Choices in the ACT

Janise Farrell

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Background

My mother, Wendy Shanley, was diagnosed with colorectal cancer in December 2009 at the age of 56. She was treated by Dr Yu Jo Chua, and underwent surgery, chemotherapy and radiation therapy. Unfortunately, the treatment did not halt the spread of cancer through her body. She was diagnosed as being in the terminal phase of the disease in July 2012.

On the 6th of September 2013, Mum was taken to the Accident and Emergency Department of Canberra Hospital, suffering with severe chest pain. She was diagnosed with pleurisy coupled with pneumonia and admitted to the Oncology ward of Canberra Hospital for recovery, pain management and radiation therapy. On the 15th of October, she was transported to Clare Holland House for “rehabilitation”.

My mother died on the 1st of November 2013 at Clare Holland House, aged 60.

Purpose and scope

I would like to tell Mum’s story to the Inquiry into End of Life Choices in the ACT for two reasons. First, Mum suffered terribly at the end of her life and that suffering was preventable. The failings in Mum’s care must be addressed and acknowledged. Second, based on my mother’s experience, I strongly believe that changes need to be made in the ACT to a) improve the standard of palliative care, and b) enact legislation to allow voluntary assisted dying.

My submission is relevant to the following of the Inquiry’s terms of reference:

- current practices utilised in the medical community to assist a person to exercise their preference in managing the end of their life, including palliative care;
- ACT community views on the desirability of voluntary assisted dying being legislated in the ACT; and
- any other relevant matter

There were very clear instances where Mum’s preferences in managing the end of her life were rejected, ignored or belittled. There were also many times when the standard of care Mum received was poor.

I have organised my submission in two main sections, dealing first with events that occurred at Canberra Hospital and second with those at Clare Holland House. The sections are ordered chronologically, rather than by importance. Indeed, the greatest failings in my mother’s care occurred at Clare Holland House.

Please note that I would be willing to appear at a public hearing as part of the Inquiry.

Disclosure

After my mother’s death, I moved to Sydney. In 2014, I joined the Voluntary Euthanasia Party and became a committee member of Dying with Dignity NSW. In the 2016 Federal election, I ran for the NSW Senate for the Voluntary Euthanasia Party. I now live permanently in Canberra and am no longer a member of the Voluntary Euthanasia Party or any other political party.

Canberra Hospital

My mother spent five weeks in the Oncology ward at Canberra Hospital. The care she received was of a poor standard. The main issues related to pain management and personal care.

Pain management

Mum was initially admitted to hospital due to pneumonia and pleurisy, but was kept in the Oncology ward after her recovery in order for medical staff to “get on top of” her pain. She was told that once her pain was under control, she could go home. The problem was that there was such inconsistency and neglect in my mother’s care that her pain could not be properly managed. The nursing staff would respond so slowly to Mum’s buzzer requesting help that they were often playing ‘catch up’ with the pain. My sisters and I were constantly needing to advocate for our mother. Problems would be discussed and decisions would be made, but notes were often either not recorded or not read and the changes would not be enacted. As a result, my sisters and I started our own notebook in which we recorded discussions with doctors and nurses, and when each one of us arrived at the hospital, we would read the notes left by the sister who had been there before us.

I was by my mother’s bedside when she asked the doctor on duty (an oncologist, I assume) about the potential to use cannabis for pain management. I recall that he simply laughed and did not respond. The memory saddens me. My poor mother was in such a great amount of pain for five long weeks at Canberra Hospital, and the medical staff would not even entertain a discussion on alternative pain management options.

Personal care

The second main issue experienced by my mother at Canberra Hospital was neglect of her personal care and hygiene needs. The nursing staff would neglect to shower Mum for days on end. As we couldn’t rely on the nursing staff to meet this basic need, my sisters and I started to shower her ourselves. As my mother lay in her hospital bed for those five weeks, she became weaker and weaker, and became more dependent on our care. My sisters and I took it in turns to do basic things for her. I remember Mum saying, “I am completely dependent on you and your sisters”. We wrote a complaint about the poor standard of care Mum was receiving (both in pain management and personal care) and placed it in the ‘feedback box’ on the wall in the Oncology ward. Mum asked us to make the complaint anonymously as she thought she would eventually need to return to the ward and she did not want staff to take retribution. She told me she had heard a particular nurse speak in a cruel fashion towards a woman she shared the room with because the woman was moaning in pain so loudly. How horrible to be in so much pain, to be so weak, and to fear the nursing staff who should be caring for you!

Transition to Clare Holland House

On the 14th of October 2013, a member of the medical staff decided that my mother should move to Clare Holland House for “rehabilitation”. Mum was reassured that the hospice did not only treat patients at the ends of their lives, but also helped weak terminally ill patients to gain the strength to go home. We were told that the hospice could better handle Mum’s pain management and rehabilitation than the hospital. She and I travelled there together in an ambulance on the 15th of October, 2013.

Clare Holland House

My mother was at Clare Holland House for three weeks before her death on 1st November, 2013. Although many of the nurses in the hospice were kind and caring, Mum experienced a great deal of preventable pain and emotional distress there. She suffered terribly at the end of her life due to the slow nature of her death, failings in her medical care, and a lack of respect for her wishes. There are many examples of how choice was taken away from my mother in many ways, which reduced her dignity and prolonged her suffering.

A slow, lingering death

A year before Mum died, she told me that I didn't need to fear that she would die in pain. While her preference would have been to have the legal right to be assisted to die, she had researched palliative care and said she knew that there were things the medical staff could do to prevent any pain or suffering.

When the hospice doctors finally admitted that there was nothing they could do for her, my mother immediately, firmly asked to be put in a coma before she died. There was no response from the doctor. Later that day, she asked me frantically, "Janise, please talk to them again. You know what to do. I want to be put in a coma". I spoke to the hospice doctor, and was told "We don't do that here". Instead they would try to make my mother's last days as comfortable as possible. They were anything but.

My mother felt pain and distress right up until the day she died. Each night, I would wake to find her in pain and call for the nurse. I remember one night Mum said, "How did you know?" How could I not? Both her little hands were raised and held in tightly clenched fists, her face in a tight frown. When Mum could no longer communicate, my two sisters and I were asked to be vigilant for signs of pain. Despite receiving morphine through a pump, with additional pain relief when called for, Mum showed clear signs of pain throughout each day - right up until a couple of hours before she died.

I realise now that when Mum had asked to be put in a coma, she had been talking about terminal sedation. She had obviously researched what her death might be like and thought this was palliative care's solution to prevent suffering. Mum should have had the legal right to end her life before that great, torturous suffering had commenced.

Instead, once Mum had moved into the unresponsive final phase of her slow death, she continued to linger on in pain, slowly wasting away for four or five additional days. We continually asked for more morphine and breakthrough pain relief to be administered. I remember on the final morning, one of the nurses entreating with the doctor for further action. The doctor increased the dosage in the pump and told us, "She will die today".

Failings in medical care

There were numerous failings in the medical care my mother received that greatly increased the amount of physical pain and mental distress she experienced.

Lack of honest communication

As mentioned previously, Mum had been told she was being moved to Clare Holland House for rehabilitation before transitioning to the care of one of my sisters or I. Gradually, it became clear to my sisters and I that she was dying. At 60 years of age, her poor little body was more frail than our great grandmother's had been at her death at 97. There were clear signs of the final phase of life

Janise Farrell

Submission to Inquiry into End of Life Choices in the ACT

that could easily be confirmed with a simple online search. However, nobody had the courage to have that conversation with my mother or us.

One day, a nurse gave my sister, who was alone at our mother's bedside, a pamphlet on preparing for the final stages of life. My sister was distraught. She did not mention it to my mother and instead called me in tears. It confirmed what we had suspected, but a conversation filled with human warmth would have been preferred. Better still, would have been acknowledgement of the dignity and worth of my mother through direct communication with her.

The following day, my husband and I were at my mother's bedside when one of the doctors did his rounds. I waited for him to have an honest conversation with her, but it was not forthcoming. My mother was asking questions about whether more radiation treatment might be beneficial and when she might expect to be discharged. He was avoidant in his responses. My mother said, "Is there something you're afraid to tell me?". The doctor couldn't meet her eyes. I said to him, "I think you should have an honest conversation with my mother. She would want to know." Mum openly asked him if she were dying, and he finally admitted that she was.

As I discussed above, she immediately asked to be put into a coma, and he avoided responding. He never returned to complete a conversation with her about terminal sedation or the medical care my mother could expect over the coming two weeks.

Neglect

There were two hospice practices that led to the cruel neglect of my mother. The first practice was that of leaving patients uncovered by bed linen. The second was the delegation of oral care to family members, compounded by a lack of communication and conflicting information from medical staff.

Leaving patients uncovered

In the first couple of days that Mum was in Clare Holland House, she told me that she had gotten up to go to the bathroom in the middle of the night and had been unable to rise from the toilet. She had pressed the buzzer for nurse assistance numerous times, and it had taken a long time for anyone to come to her aid. When they finally did, they left her in her bed, uncovered by the bed linen. It was mid-October, and Canberra was still experiencing cold nights. Mum had woken feeling terribly cold, but had not been able to reach her buzzer. She lay there in the cold for hours before someone attended her in the morning. My mother and I had thought it had simply been an oversight, caused perhaps by the hurry to get her back into bed. However, a further tragic incident occurred that revealed that leaving patients uncovered may be a regular hospice practice.

In the final week of my mother's life, when she had lost the ability to communicate verbally, my sisters and I slept at the hospice, taking it in turns to go home to shower and get clean clothes. One evening, I went home and found that the weather had suddenly turned bitterly cold. The temperature that night was forecast to be -2°.

When I returned to the hospice, I found the bed linen had been removed from my mother. I expressed concern at this and was told that Mum had had a fever, so they had removed the bed sheets. As her fever had now subsided, I asked that the linen be returned. One of my sisters was reluctant for this to happen. The nurse on duty tried to assure us that there was no need for my mother to be covered because at this point, all the blood in the patient's body would leave their limbs and centre in their torso and the person would die. She said Mum wouldn't feel the cold. I was still unconvinced and my sister was open to hearing an alternative view, so when a more senior staff

Janise Farrell

Submission to Inquiry into End of Life Choices in the ACT

member came on her shift, I again explained that the temperature was much colder outside than people in the hospice would realise, and that it was forecast to drop to -2° overnight. I said that Mum had had a fever, but that it had subsided several hours ago, and that surely the bed linen should be returned. This more senior nurse also said that the blood would now pool in Mum's torso, her limbs would change colour and go cold, and she would die. There was no need to cover her from the cold, and with the covers off, we could see Mum enter this phase. As this advice was coming from a senior staff member, I reluctantly agreed.

That night, I was vigilant, as always, to sounds from Mum's bed. I thought she made some sound a couple of times, but when I got up, I couldn't see if anything was wrong. In the morning, when everyone was up and the nurse came back in to the room, Mum was struggling to speak. She seemed to be saying, "Go!". I said that word and other guesses at her intentions, but she rejected them with a slight shake of her head. Finally, I realised that she was trying to say, "Cold!". I touched her arm and it felt like a block of ice. I immediately called for the covers to be put over her again. Mum's limbs eventually returned to their usual warmth. She would not reach the stage described by the nurses for many days, and she had been left uncovered in the cold for a full night. The cruelty of that event has haunted me for the five years since Mum's death.

Delegation of oral care to family members

On another occasion that I had returned home, the hospice nurses showed my sisters how to care for Mum's lips and mouth. When I returned, there were glasses filled with water and swabs for wetting the mouth, and also spray bottles of water. Mum's mouth had dropped open at this point, and she was unable to speak.

At one point, I tried to wet Mum's lips with a swab and they started to bleed. I tried to spray inside her mouth, but my sister told me that one of the doctors had warned her against using the spray as it can pool in the back of the throat. I was concerned that Mum's mouth would be getting terribly dry, but saw that the nursing staff seemed unconcerned by her oral care. I thought perhaps it was just something to expect at the end of life – another thing to add to the list of other seemingly preventable, painful indignities Mum had to suffer.

I finally realised that no-one was caring for Mum's mouth. I stayed in the room one morning when a new shift of nurses came on duty and the senior nurse was briefing them all on my mother's situation. I heard her say, "We have delegated the care of her mouth to her family". I was horrified! No-one had told me that we were solely responsible for Mum's oral care. No-one had shown me what to do. In addition, clearly one of the doctors had given conflicting information to my sister and she was now afraid to perform a key aspect of that care and had also advised us not to perform it. When I was alone with a nurse, I asked if the nursing staff could take over Mum's oral care. I urged her to see to it right at that moment. She found that Mum's tongue was firmly stuck to the bottom of her mouth and couldn't be freed. I could see that she was shocked, but was trying not to show it. That will also haunt me all my days.

Problems with pain management

As had occurred at Canberra Hospital, the medical team at Clare Holland House had difficulty managing Mum's pain. As mentioned previously, although Mum received pain relief through a pump with additional breakthrough injections, she experienced pain right up until the hours before she died. There were two additional areas of concern regarding pain management at the hospice.

Janise Farrell

Submission to Inquiry into End of Life Choices in the ACT

The first issue was that the hospice staff left my sisters and I to decipher pain symptoms without knowing what they were. It was easier when Mum could speak or, as I have discussed above, clench her fists tightly in pain. Once Mum could no longer speak or move, we were left watching for signs of pain on her face. A furrowed brow, eyes closed tight? Was that a flicker of pain? How many grimaces do we need to see before it's OK to call for the nurse? We were not trained professionals and no-one had told us what to look for or when to worry. It was only on the day Mum died that a nurse finally mentioned that fast breathing was a pain symptom.

The second issue of concern was that when a nurse had put Mum's pump between her pillows, a tube had come out, and instead of being pumped into Mum's arm, the morphine was leaking into the pillow. No-one had noticed this until the pillow was already soaked wet with the drug. When the senior nurse became aware of this, she immediately went into 'damage-mode' making excuses and guessed-at assurances. No apology was given. Even when my sister and I took the nurse out of the room to express our alarm and distress, the nurse made excuses and refused to apologise.

Lack of respect for Mum's wishes

In addition to the inability to have an honest conversation with my mother, the hospice staff also showed a disregard for Mum's wishes.

Mum had not wanted to be moved or rolled while she was able to communicate due to the discomfort and pain it caused. The nurses had respected this at that time. However, once Mum was unable to speak, they did what they wanted with her. At times she whimpered in pain or fright, and it breaks my heart that her last words were a frantic, "Let go! Let go!" as the nurses rolled her body so that they could change her bed linen. At that point Mum had been in an unresponsive state - eyes closed, jaw slack - and hadn't spoken for two days. A day or two later, the full team of nursing staff came in to move Mum from her mattress onto an air mattress. Mum screamed out in fright the whole time she was being moved, and all I could do was stroke her hair and try to tell her it was alright. On the day they knew Mum was going to die, the nurses told us they were going to roll her to change her sheets and wash her. Up to this point I had demanded to be present on each occasion that she was moved, but by this point I was so weak and traumatised that I couldn't stay in the room. When the nurses had finished, I asked if Mum had been alright. They told me that she had murmured in complaint. It is something my sisters and I have discussed several times over the years. Why was it necessary to move her, against her will, even on the final day of her life? On that day it was clearly for their own convenience. It was not out of concern for my mother and it certainly was not in respect for her dignity and right to choose how to end her days. I can't see how this aspect of palliative care qualifies as *care*.

Another time that the nursing staff showed no respect for Mum's rights and dignity was when they gave her an injection against her wishes. We had noticed that Mum was showing signs of pain and distress, so we called the nurse in to provide more pain relief. However, when the nurse came into the room, Mum tried to raise one hand to her face - the arm moving, but the hand limp at the wrist. The nurse panicked and prepared to quickly inject my mother's arm with pain relief. Mum's limp hand then darted towards the needle, trying to stop the nurse from injecting her. The nurse did it anyway, and Mum again drifted off. I believe now that Mum had been trying to alert us to the pain and discomfort she was experiencing as her open mouth dried out and her tongue became stuck. I believe she may have been trying to communicate this fact while she was more lucid. Whatever the reason, the nurse ought to have tried to understand Mum's concerns been responsive to the indication that she didn't want to be injected at that point.

I believe the lack of choice and control over what happened to her would have impacted greatly on Mum's sense of dignity, and would have caused emotional distress.

Personal impact

It has been an ongoing source of regret that I did not make a complaint about my mother's treatment at the hospice right after she died. I had wanted to do so immediately after we had completed Mum's funeral service. However, the trauma of the ordeal of watching Mum die such a cruel, slow, painful death haunted me to such an extent that I could not speak of those events to anyone but my husband and I would break down any time I thought about particular memories. Instead, I joined the Voluntary Euthanasia Party and Dying with Dignity NSW and campaigned for law reform in NSW. I eventually saw a psychologist in Sydney for post-traumatic stress disorder. Even now, five years later, I must have a glass of water beside the bed when I go to bed at night. If my mouth gets dry, I wake up in panic. If I wake during the night feeling cold, I also panic. I think about Mum's death every day.

Conclusion

The day my mother finally died surrounded by her heartbroken daughters, and the initial shock had subsided, the very first conversation between us was how cruel and slow her death had been. A cruel, lingering death, watched by the hospice staff from a distance, the doctor visiting my mother's bedside for just five minutes every morning.

It is very clear to me that currently, the rights and dignity of terminally ill patients are not respected. The medical staff were unable or unwilling to have frank discussions with my mother about her pain management options, the fact that she would soon die, or the way her dying days would be managed by the medical team. Her wish not to be moved was respected for two weeks while she could speak and look staff in the eye, but she lost the right to make a choice once she lost the ability to speak (or so it had seemed – her final words of "Let go! Let go!" came out clearly through her pain and distress). She lost the right to refuse treatment, and her comfort was a secondary priority to the nurses' convenience.

Mum's experience showed me that staff at both Canberra Hospital and Clare Holland House rely far too greatly on a patient's family to meet essential care needs. We had to shower Mum ourselves at Canberra Hospital, and we were left alone with Mum to identify signs of pain and to care for her mouth at Clare Holland House. There was not enough communication given to us to do either of those things at the hospice. Furthermore, a patient's family is going through trauma and should not be expected to pick up the slack for an overworked or short-staffed nursing team. I recall that when I told the nurse that we would like the nursing staff to take over the care of Mum's mouth, she said, "I understand. You would prefer to be daughters, rather than nurses". We never should have been left to do any of the nursing.

My mother had been a trainee nurse before she married in the early 70s, and that time had left her with a strong belief in the right to euthanasia. Mum should have had the right to choose an assisted death. The two months of pain and suffering at the end of her life could have been avoided. The last week was particularly cruel – something akin to torture – and she should not have had to endure it.

Recommendations

Based on my family's experience, I recommend that:

1. residents in the ACT be given the right to choose an assisted death to end their pain and suffering;
2. medical staff respect the rights and dignity of terminally ill patients by answering patients' questions directly and engaging in honest conversations about end of life issues;
3. the quality of palliative care in the ACT be greatly improved;
4. the families of dying patients be provided with more support, including more visits by nursing staff to the patient's room each day, and not be used to provide care that ought to be given by nursing staff;
5. residents of the ACT be given greater choice in end of life care providers, including quality, secular palliative care providers.

I believe that telling my mother's story is one of the most important things I have done in my life. I hope that in doing so, I can help others avoid such a death.