

Mrs. Susan Lackner



Inquiry Name: Inquiry into End of Life Choices

Date of Submission: 28th of July 2015

SUBMISSION CONTENT:

My mother recently passed away in an aged care facility after a long illness with Frontal Temporal Dementia (FTD). I believe a number of issues were highlighted during her illness that should be taken into consideration into this inquiry.

Advanced Care Plans

As recommended by the geriatrician who diagnosed my mother with FTD we immediately put in place Power of Attorney and an Advanced Care Plan. We were referred to Caulfield Hospital where we met with an expert advisor who was trained in drawing up advanced care plans. At that stage my mother was still lucid and able to make decisions about her end of life. My mother opted for all active medical treatment to be stopped when she required full time care in an aged care facility. She specifically requested she be kept comfortable, be allowed to die with dignity and be pain free.

On admission to the aged care facility nearly two years later, I provided the advanced care plan to staff, that had been signed by her husband, power of attorney and her medical practitioner. It soon became apparent that the staff viewed this document as irrelevant and gave preference to their own. Unfortunately at this stage my mother was not competent enough to inform them of her wishes. When I informed them of my mother's wishes as per the advanced care plan they became quite uncomfortable and stated that she was too well for all active medical treatment to be ceased. My father and I also had a meeting with her new doctor who was recommended by the facility, as her current doctor did not travel to that facility and he also refused to cease all active treatment as per my mothers wishes.

In my experience there appears to be little education on advanced care plans that are completed outside of aged care facilities. The advanced care plan we completed at Caulfield Hospital was much more robust, independent, considered and took several weeks to complete, and most importantly it fully represented my mother's wishes. It is my understanding that as my mother had an incurable disease, she had a legal right to request all active treatment to be ceased at her discretion. There appears to be a lack of education about this and possible legal concern about implementing very clear and considered instructions. Consequently, the medical staffs lack of education and legal and ethical concerns resulted in my mother's end of life wishes not being implemented.

Training of staff in Palliative Care

Four days before my mother passed away it became apparent to our family, the nursing staff and the doctor that our mother was in the final stages of her life. She was in considerable pain and required narcotics to control her pain. She had also stopped eating and she stopped drinking the next day. The doctor was called in as any movement resulted in severe pain. As a family we requested that she not be in any pain and were advised that this would involve implementing an active palliative care regime. We agreed this was the best way forward and honored my mother's end of life wishes. Unfortunately, it became very apparent that there were significant differences in the medical staff's understanding, training and implementation of final stage palliative care treatment.

We are a family who has medical knowledge. I was trained and worked as a State Enrolled Nurse and my husband is a General Medical Practitioner and my mother's sister is a registered nurse. Consequently, we are aware of treatments available and signs that indicate when a patient is uncomfortable and in pain.

My sisters and I never left my mother side for three days, as she died. During that time the qualified nursing staff, both registered and state enrolled nurses only saw my mother to administer medication. This was usually done at the request of our family and there were numerous occasions when this was not done, as they believed she was not in pain. The personal care attendants were responsible for turning my mother every 3 hours and on the second day I requested that I be present when they did this. My mother became clearly agitated, grabbing them, and groaning. There were times when there were tears in her eyes and she was crying. The distress my mother exhibited was not witnessed by the daytime qualified nursing staff as they did not turn her and when this was communicated to them, they did not act on it. There were many times when my mother was left in pain and the nursing staff were reluctant to provide pain relief for fear she would be over medicated. This act contravened my mother's end of life wishes and was quite simply not good enough.

It was very evident that some staff were exceptionally trained in palliative care. These staff members had an excellent understanding of how to look for and monitor pain and were comfortable providing as much pain relief as need to ensure my mother was comfortable. The difference with these staff members is they were not fearful of my mother dying, understood the process and gently and caringly supported our family and comprehensively explained when and why they were giving her pain relief. In comparison, other staff members appeared poorly trained in palliative care, fearful of my mother dying from the administration of morphine and reluctant to involve our family in what they were doing. The actions of these staff members were very distressing to my family and failed to honour my mother's end of life wishes.

The doctor treating my mother also appeared to be poorly trained in advanced palliative care treatment and blasé in his treatment of my mother. The communication between the treating doctor and the staff left little to be desired. The doctor failed to adequately communicate his orders and consequently the standard order of morphine was not written up. This resulted in my mother only

being eligible to a PRN morphine order, which is given at the nurse's discretion. The doctor did not see my mother in the last 48 hours of her life and when we requested 8 hours prior to her death for medication to dry the secretion in her chest, he refused. This medication is standard treatment in situations such as this. My mother's breathing was very loud and her chest was wet, and the noise was so distressing I had to remove my hearing aids and play music. The treating doctor did not review her and the staff appeared to be unaware of the treatment available. My husband specifically requested this medication and was refused without any review of my mother by the treating doctor.

Five hours before my mother died the nursing staff informed us they believed my mother was having too much morphine, even though she was wincing and had tears in her eyes. They informed us they were reducing the administration of morphine. My husband, a medical practitioner had to call her doctor, a palliative care team he worked with and advocate in a tense and hostile environment for my mother to be kept pain free. It was at this point the treating doctor realized the standard order of morphine had been miscommunicated and not written up. Three hours of this order being implemented my mother passed away. Prior to the last three hours of my mother's life, her end of life wishes were not implemented or respected and she was consequently not pain free.

Support and Communication with Family Members:

As I indicated earlier, there were staff who were fantastic during my mother's final days and there were staff who were poorly trained and detrimental to my mother and our family during her last days. Once again, the lack of training and education of some staff members were clearly evident and this has resulted in our family feeling very traumatized by our mother's death.

The Rights of the Patient:

Unfortunately my mother's end of life wishes were not implemented or respected. As a family we took all the steps available to us to ensure her wishes were executed, yet this did not occur. My mother's autonomy, dignity and rights were not respected. Her humanity was denied to her in the hours of her greatest need. Clearer guidelines, adequate funding and appropriate training are needed. Only staff experienced and trained in palliative care should be able to care for the dying. Legislation needs to support staff to ensure the rights of the dying are honored. Advanced Care Plan should be legally enforceable documents.

In Conclusion:

Each and every one of us will at some stage die. I believe it is the wish of every human that it would occur in a dignified and pain free manner. There is an opportunity for this inquiry to make a difference, address the fear of dying and see it for what it is, a natural process we will all go through; and create an environment that is nurturing, connecting and supportive for all people involved. I strongly urge all the members of this inquiry to show leadership, courage and integrity and make changes that will positively affect us all some day. Please do not let my mother's death be in vain.