

## Submission to Parliamentary Inquiry into End of Life Choices

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### **Introduction**

My submission is informed by the death of my father, Ken. I think his experience can offer valuable insights into how thorough and respectful communication, provision of timely information and careful medical assessment can result in a sound decision to terminate one's own life.

Sadly my father's experience also demonstrates what happens when a considered and legal decision to end one's life of extreme suffering, is not twinned with an effective and humane method of implementing that decision.

### **Argument**

My argument is that a regulated decision making process that promotes the wishes and safeguards the rights of a terminally ill person can result in that person making sound and informed end of life decisions.

A decision to end life made within that process (with necessary checks and balances) should be respected and a humane method to end life should be available.

That method should be transparent and subject to strict regulation and oversight to ensure that it is humane and professionally implemented and reflects the wishes of the terminally ill person as expressed in the regulated decision making process.

### **Background**

My father was 59 years old when he first experienced symptoms of what would later be diagnosed as Motor Neurone Disease (MND) - a disease that cripples the body and leaves intelligence and understanding untouched.

Over a space of six years he gradually lost the use of his fingers, hands, arms and legs. He lost his power to speak and to swallow food. He had to be toileted, usually by his wife who nursed him for the full duration of his illness. He dribbled and so, as an intelligent civil engineer (probably a similar age to some of you on this Committee) he spent his long, long days in one chair by a window with a large bib on.

As his speech became difficult to understand and then non-existent he would communicate using an E Tran board. This is a transparent plastic frame printed with colour-coded letters of the alphabet. He communicated with us by indicating a colour and then a segment of the board. We could then write down the letter he was referring to and gradually piece together words and short sentences.

At some stage during the development of his symptoms, when my father could no longer eat food he elected to have a feeding tube inserted into his stomach. This enabled PEG feeding and it is how he consumed his food and drink.

### ***End of life decisions***

Approximately 5 years into his disease and a considerable time after the PEG was inserted, my father asked me, via the E Tran board, whether he could end his life.

I researched the law and was able to tell him about the 2003 Victorian Supreme Court case of *Gardner: re BWV*. The Court proceedings were initiated to obtain a ruling on whether artificial nutrition and hydration delivered through a PEG tube regarded as "medical treatment" or "palliative care". Under the *Medical Treatment Act 1988*, "medical treatment" may be refused, but "palliative care" may not. The definition of "palliative care" in the Act includes "the reasonable provision of food and water".

The Court decided that PEG tube feeding was a "medical treatment" and so can be refused by a guardian or an agent authorised to make medical treatment decisions on behalf of a person unable to make their own decision.

Because my father was PEG fed he had the option to cease that treatment. However, under the current law, this meant he would die of starvation and dehydration.

### ***Process of decision-making***

Armed with this information, my father delayed further steps for the time being. However approximately 6 months later he asked me, via his E Tran board, to contact his palliative care doctor to discuss his options.

My father had had intermittent contact with the palliative care doctor for approximately 2 years. This was usually when my father went into the palliative care hospice for occasional two-week stays to give my mother respite from the demands of 24/7 care.

This pre-existing relationship with the palliative care doctor meant that he had met when my dad could still communicate verbally to some extent and they got to know and trust one another.

I spoke by telephone to the palliative care doctor and organised for dad and he to meet and discuss his feelings. The doctor called at our home and spoke to my father. I understand my father indicated to the doctor that he wanted to cease PEG feeding.

The palliative care doctor then organised a family conference at our family home. My father, mother, brother, the doctor and myself attended. During this meeting, my father and the rest of the family each talked about what he wanted to do. This discussion was facilitated by the doctor. Everyone was able to talk openly – dad via his E Tran board.

Needless to say, it was a harrowing discussion but it was respectful, ordered and allowed the views of everyone to be heard and considered. The decision-making remained my father's. He knew that the muscles in his eyes were

weakening and once he could no longer keep his eyes open and indicate letters on the E Tran board, he would have no effective way to communicate his wishes.

The discussion ended with the views of all family members being known – albeit not necessarily accepted. My mother desperately wanted my father to reconsider his decision to cease PEG feeding.

The palliative care doctor suggested that if and when my father was ready to act on his plans to contact him.

I believe the decision making process available to my father was very good. . I was able to get him information about the law when he sought it. He had a pre-existing relationship with a doctor who knew him and his disease. He had access to this doctor when he needed further information about his end of life choices.

Discussion of those choices took place in an open and transparent way. The discussion was facilitated so that the views of all the family were all heard in a calm albeit emotional atmosphere. It was always very clear that the decision was my father's to make. There was no hurry to resolve the issue – it was up to my father to take each step, if and when he wanted to.

### ***Death***

Sadly, the compassionate and considered decision making about my father's end of life choices was followed with the cruel reality of his death.

Because my father had PEG feeding (medical treatment), he had options to end his life that would not be available to other people who were still feeding via mouth (palliative care). However while the law respected his right to decide to end his life, it gave him no help to do it and insisted that he must die slowly of starvation and dehydration.

Dying this way can take days or even a fortnight, so my father needed access to reliable palliative care to relieve his suffering. Accordingly he asked to be admitted to the local palliative care hospice where he knew he would have quick access to pain relief if he needed it. He did not want to risk being without necessary pain relief at home. I suspected he also felt that his family would also need the support of the hospital staff rather than watching him die slowly at home.

A day in the week the following the family conference was set for his admission and he (and we) counted down his days left at home. His final morning at home was heart breaking. My mother dressed him and he thanked her (using the E Tran board to dictate the message to me) for their happy marriage and for caring for him.

He then asked to see, for the last time, the garden that he had planted. He sat for a long time in his wheel chair on the front veranda, with my mum, and just

looked at the garden until the disabled taxi arrived and he left his home forever.

While the staff at the hospice were kind and considerate, there was no escaping the necessary steps of dying in this way. Mucous solidified in the back of his throat and needed to be regularly prized out with cotton buds, causing him to gag. His mouth was dry and could only be swabbed with water. Nurses, unfamiliar with his routines, tried to turn and bathe him and struggled to get him comfortable. He was eventually sedated when muscle cramps were so overwhelming and painful for him. I hope the sedation was effective in managing that pain. He died after 12 days.

### ***A different death***

I cannot help thinking how much better my father's death could have been. A thoughtful and respectful decision making process allowed him to choose to die. Sadly, he was not then offered a humane option to implement his decision, such as a lethal injection or medication.

Such an option would have spared him the physical distress of dying over 12 days from lack of food and water – his only choice under current law. It would also have spared him the grief of saying goodbye and leaving his home, garden and neighbourhood to die slowly in a hospital a few kilometres away with strangers tending him and his family watching his slow demise.

Those who argue against euthanasia rightly highlight the importance of each person being truly free to make their own decision about their end of life. I feel that my dad's decision-making process had good checks and balances and that his decision was sound and based on a process with integrity. It demonstrated to me that such decision-making can be made carefully and ethically to protect the rights of the terminally ill.

To make such end of life decisions meaningful, the decision maker should also be offered the means to humanely implement that decision by controlled and supervised access to lethal drugs.

### ***Suggestions for future policy development***

Based on my personal experience with my father's illness and decision making I would make the following comments about any decision making process developed for those people who are not cognitively impaired:

- Information should be available to all the parties to outline in simple terms the legal, medical and process issues to be considered;
- Access to a medically assisted death should be available to terminally ill people whose quality of life is severely limited by their condition;
- The terminal nature of the illness must be beyond dispute;
- The impact on quality of life should be objectively apparent, for example, severe limitation of quality of life would be present where the normal elements of life can no longer be enjoyed – independent movement, verbal communication, eating, drinking.

- A decision making process should involve treating doctors but also an independent doctor and other trained professionals such as a social worker or psychologist.
- The immediate family of the terminally ill person should be consulted but discussions should be facilitated by an independent third party who ensures the terminally ill person's will is not being overborne in some way – express or subtle.
- The independent third party (possibly medical or allied health staff but not necessarily) should be specifically trained and qualified in this type of facilitation. Qualification should be accredited.
- There may be a number of facilitated end-of-life discussions over days, weeks or months depending on the circumstances or people.
- The involvement of medical and allied health staff in these discussions would be mandatory.
- The process of decision-making would be documented and an independent person would certify the terminally ill person's decision was made according to the decision-making process.
- A cooling off period for all decisions by the terminally ill person would be required.
- If the terminally ill person decides to die, then they should be offered a range of options to implement that decision ranging from palliative care to medically prescribed medication that would end life quickly and humanely.
- There should be a clear "audit trail" of all decision-making undertaken and the means used to end life documented and listed on the death certificate.
- There should be a means to challenge the decision making process to a body like VCAT if a person sufficiently connected to the terminally ill person is concerned with the integrity of that process. However if the process is found to be sound, through a thorough examination of the documented decision making then the decision of the terminally ill person is to be respected and implemented.
- while the legal process and review arrangements should be clear and transparent they should not be made overly complicated, time consuming or onerous. Any review process should be expedited and allow for a visit to the terminally ill person by a tribunal member, rather than a legalistic, formal hearing.

A. Woodger  
29 August 2015

Ms Anne Woodger

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