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From: Inquiry into End of Life Choices POV eSubmission Form
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SUBMISSION CONTENT:

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I am not qualified to comment on these Terms of Reference from either a medical or legal perspective.

I merely wish to offer my view, as a private individual, gleaned from my limited personal experience of caring for, or being close to, 5 loved ones at the time of their deaths, over a period ranging from 1965 to the present.

I attended 5 close friends - including family members - before, during and after their deaths:

- # in 1965, my father, at age 49, from lung cancer;
- # in 1986, my mother, at age 70, from cancer of the pancreas;
- # in the 1970s, my father-in-law, of stomach cancer;
- # a close friend (father of 2 young daughters,) of motor neurone disease;
- # and my 93 year old uncle - also from cancer.

In the 1960s, I remember that choices were very limited. I recall no discussion of palliative care. The only 'option' that seemed to be available was for my father to be transferred from home to hospital (Frankston) where he simply lingered and wasted away over what I recall to be several months (but which may have been merely weeks - in any case, for a period much longer than he would have wished, given the agony he was suffering at the end.)

That period was characterised by the breakdown of his bowel function - and increasingly painful and distressed breathing. His breathing was so laboured that we could hear his fighting for air the moment we opened 'the back door' of the hospital - his room being at the very end of a long corridor. His death was agonising, and so very slow, slow ...

In contrast, my mother was cared for by a very caring and skilful oncologist, who no doubt, by 1986 had

'more weapons in his armoury' than did my father's doctor, back in 1965). He was able to keep her in relative 'comfort'. (At least, I recall that it was at this time that I first heard the term, 'pain management'. My sister and I are convinced that my mother and her doctor 'had an understanding' about 'what was to happen at the end'. Towards the end, he fortuitously appeared one morning when we were visiting together... we were asked to leave her room for a few minutes. When we returned, she appeared to be in a deep, calm sleep, and, while he was still on his rounds, she died.

My father-in-law spent his last days in a bed in "the Heidelberg Repat", as he used to call it. He experienced severe pain in his final days, but he was eventually fitted with a self-regulating device that administered - I guess - morphine. When the pain became unbearable, he kept increasing his dose - until he died. A humane solution, in my view, as long as the dying person retains the capacity to 'turn the dial'.

In my opinion, my friend suffering motor neurone disease, had the worst death. The expressions in his eyes indicated that he was conscious of what was happening around him, but he could not speak. With one finger tracing - on his sheet - one letter of the alphabet at a time, he indicated that he wanted us to look after his wife, who had/has multiple sclerosis.

But his illness had been very protracted. Why had not an opportunity been afforded him to discuss options - at least before he lost the power of speech?

My old uncle was taken to a private hospital a few days before his death. His doctor visited, and - though not in our presence - apparently gave detailed instructions to the nursing staff.

Subsequently, the nurses asked us to alert them if there seemed to be an increase in his discomfort (such as writhing). Each time we raised the alert, a nurse would enter his room and adjust the medication he was being administered via a drip. This continued for almost 24 hours, until he ceased to 'writhe' altogether.

The observations I want to make about these experiences are as follows:

1. With the exception of my father in the 60's, doctors attending the other 4 dying people seemed actively involved in their deaths.

So the view that doctors take a 'hands-off' approach to dying, and that, apart from pain management, allow nature to take its course, is a fiction.

It surely is safe to assume that the majority of doctors who are 'actively involved' in this way are motivated by a desire to ensure that their patients suffer as little as possible as they near their ends. Such doctors should be afforded the full protection of the law, and not be forced to maintain the fiction of 'natural death' when actually, 'physician-assisted' death is what is occurring.

I believe that, in the 5 cases I have outlined, at least 4 of the people described would have wanted their physicians to be able openly to assist them to achieve a dignified, painless AND EXPEDITIOUS 'departure'.

2. Making allowances for the paucity of options probably available in the 60s compared with the 80s and after, attentive care administered by doctor-led nursing staff seemed to produce the most comfortable conditions for dying, (Though one could speculate that even some of these deaths may have been unnecessarily prolonged).

3. However, with the possible exception of the case of my mother and her very attentive (but discreet) doctor, in none of these situations did there appear to be an opportunity to actually establish whether the process was what the dying person actually wanted.

All 5 of these dying people were of sound mind, and - apart from the friend with motor neurone disease - were able, to some extent to articulate their needs.

But we gained the impression that - apart from a vague understanding that they would be kept as free of pain as possible, any other needs they may have had remained a mystery.

I believe that the availability of a euthanasia option - in the form of a physician-assisted death - would constitute a progressive reform.

I appreciate that the legal ramifications are far from simple. But nor are they insurmountable. If no obligation is attached to the role of either the doctor or the dying person, and a range of options is proffered the latter, then the current state of subterfuge - with its high risks for doctors and its inevitable narrowing of choices for dying people - could become a thing of the past.

Fortunately, as the Committee is undoubtedly aware, there are by now, a number of 'cases' around the world that may be studied for any lessons that might profitably be drawn for Australia.

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File1:

File2:

File3: