

28 July 2019

25 Meadowvale Road  
Athelstone SA 5076  
Ph. 8336 4114

Ms Leslie Guy  
Secretary to the Committee  
Joint Committee on End of Life Choices  
[jcendoflifechoices@parliament.sa.gov.au](mailto:jcendoflifechoices@parliament.sa.gov.au)

Dear Committee members,

My father died in 2014 after two years of persistently asking for his life to end. No-one could legally act on his request. So he starved himself to death.

This was a man who, throughout his life, had made strong, vital contributions to his community.

- In his hometown of Broken Hill, at the point when 2000+ students were enrolled at the local high school Bill was instrumental in the campaign to have a second high school built.
- He was active as a member of the Parents and Citizens Association of the three schools his seven children attended over a period of twenty years, including representing the local associations at state conferences on a number of occasions.
- Bill successfully campaigned for the establishment of a Lifeline service in Broken Hill, a remarkable achievement in that it was only the third one in Australia. He went on to become a Lifeline counsellor once it was established and served on the Board.
- He spearheaded a committee to found the Broken Hill Community Credit Union of which he was the Inaugural Chairman, fulfilling that role for ten years until he moved to Adelaide.
- Bill's Christianity saw him active in the Methodist and Uniting Churches as a choir member, church trustee, Sunday School Superintendent and more than 60 years' service as a lay preacher.
- In his 70s he became part of a community choir.
- In his 80s, he became a volunteer for Telecross, on a weekly roster to phone elderly and infirm people to ensure they were well, alerting authorities if the call went unanswered.

The final two years of his life were spent in aged care as a consequence of a generalised diagnosis of dementia ( which was never substantiated with detailed tests). He had difficulty finding the words he wanted to say, and as his stay in care lengthened he was increasingly unable to form a complete sentence. Despite declining speech capability it was clear that something was still happening in his brain, and when I visited his face would light up as if the sun was rising. Then he would always attempt to communicate, more unsuccessfully as time went on. His intense frustration at those failures was clear. When he did speak his words were frequently about wanting his life to end.

For a man of his calibre to be reduced to almost total dependency was a pitiful sight. Along with the dementia came increasing incontinence so that I could no longer take him out for a coffee. The first time it happened, as the urine dribbled down the inside leg of his pants his eyes filled with tears and, in the best sentence he could form, he said "I didn't do it", his way of saying it was beyond his control.

He told his children in whatever way he could of his wish to die. Over a full minute he struggled with forming a sentence, eventually managing to tell me “My life has ended,” then pointing to a staff member he continued, “but these people are keeping me alive.”

On another occasion he struggled with his words, slowly and angrily forcing out “I’d be better off ...” before the sentence trailed away. I prompted him to continue and the sentence ended “in the ground”.

A few months before his death he almost got his wish. He had suddenly become ill, and was having respiratory difficulties, but a GP had visited and given him an anti-biotic injection which ‘saved’ him. Staff had an oxygen bottle nearby, but they informed me that each time they tried to put the mask on he knocked it away, even though he was semi-conscious. I told him I was there, and thinking he would let me put it on attempted to and got the same reaction but accompanied by a fierce statement of “I want to go!” Then I understood. When I explained to him that it was only oxygen, and it would make his breathing easier but not stop him from dying, he relaxed, allowing me to apply the mask.

Bill’s walking declined to a shuffle, he lost the capacity to shave, shower or toilet himself, even to wipe his own backside. In the last two months of his life he could not remember how to move himself from a standing position to a seated one and vice versa. It was a matter of coaxing him through the process with encouraging comments such as “Now bend your knees”. He was unable to grasp his walking frame without someone helping him to wrap each hand around the handles. He had no say in anything, ranging from the food he ate to what he wore, to the time he was put to bed. His frustration showed in anger and physically lashing out at staff – it seemed to me that shouting at them “Don’t touch me” was one of the last vestiges of control of his body and life that he had. Around this time when my brother visited him, Bill was sitting asleep in his chair. When he gradually opened his eyes and recognised his son he shook his head and moaned “Why am I still here?”

Given a life with consumption of neither alcohol nor tobacco and with genes that gave him no cardio-vascular or cancer risk, his body was not going to give up easily. In institutionalised care he had no access to knives, poisons or prescriptions to end his life. Indeed the physical decline was such that he would not have been able to use many common methods of suicide. So he began refusing food and drink. As his legal guardian I had instructed he was not to be forced to eat and this was observed. In the final 24 hours of his life renal failure and respiratory distress set in. Twelve hours before death morphine was administered as required to relieve this.

Bill died relatively peacefully in ‘pharmacological oblivion’ but unable to recognise or respond to me. A few months short of his 92<sup>nd</sup> birthday he finally had his wish to die granted, and – maybe not accidentally – one day after the birthday of his predeceased wife. But why did it have to be so prolonged with independence, dignity and control removed? He had made his contribution to society. Why would society not let him go?

**I ask members of the Committee to tell me what was served by prolonging his life in this way? I ask members of the committee - if you had been brave enough to face my father and tell him that he had to continue with his hell on earth what reason would you have given?**

#### Committee considerations

Committee members should not make the mistake of thinking the need for voluntary assisted dying is about unrelievable pain. That is a misunderstanding. Most pain can be managed. It was not physical pain that motivated my father, but an existential , unbearable pain.

You will be told that palliative care is the solution, but my father did not have a terminal medical condition that would have qualified him for palliative care and there would have been many ahead of him in the queue. Please consider his situation against any such claims.

But even if he had qualified, what would palliative care have done for his incontinence, for his inability to toilet himself, his difficulty in moving between standing and sitting positions, his struggle to hold the handles of his walking frame; his fight to express himself? The control and dignity he desired was completely out of reach.

I note the title of your committee: the Joint Committee on End of Life Choices, and it is that last word 'choices' which gives me hope. My father was left with only one choice, which was hardly a choice, that of slow suicide.

I know the Committee will be presented with arguments about the risk of abuse or misuse of any legislation. What I ask members to consider is whether the mere potential for risk outweighs the miserable, dehumanising situation of many elderly people who have served their time and who, like my father, "want to go". You are being asked to balance something which **might occur and for which there is minimal evidence** versus the reality of what **is happening** on the ground: which one should be given primacy?

If potential abuse or misuse is advanced as the reason for not legalising voluntary assisted dying, then what is to be done about the road toll? Cars are extremely dangerous, with a far higher associated morbidity than any experience of VAD anywhere in the world. Unlike voluntary assisted dying, almost all who die through car crashes have had their lives ended involuntarily. Yet no-one suggests cars should be removed from our lives.

Similarly, Australia's taxation laws are often avoided, evaded, abused and misused. It does not stop our parliament from introducing new taxation laws to ensure people pull their financial weight in our economy.

One of the terms of reference you are considering is whether legislation similar to that of Victoria should be introduced. My answer would be that legislation should be introduced, but not of an impossibly restrictive nature with 64 discrete steps as in the Victorian law.

My father did not have a terminal illness, so he would not have qualified in Victoria. Yet dying is a process, and clearly he was dying. Under Victorian law he would most likely have been deemed as unable to make a request for VAD given the dementia diagnosis. Yet he asked for his life to end as often as he could form the sentences, and he asked it of anyone who had the patience to listen as he struggled to spit out the words.

A civilised society would have granted my father's wish.

Yours sincerely



Hon. Sandra Kanck  
[sandramyrtho@internode.on.net](mailto:sandramyrtho@internode.on.net)