

Submission to Legislative Council's Legal and Social Issues Committee by R. Henry

Terms of Reference

"The Legislative Council's Legal and Social Issues Committee is interested in the community's views, insights and experiences in relation to this issue, to inform its recommendations to the Parliament. The Committee will examine:

- How current medical practices and palliative care can assist a person manage their end of life*
- How this issue is managed in other Australian and international jurisdictions*
- Potential changes to our legislative framework."*

I direct my response to the Committee's Terms of Reference above using the summarised question from DWDV, namely: ***Are Victorian laws adequately meeting people's expectations regarding medical options available at the end of their life?***

Now 78 years old, I have seen many of my cohort of friends and relatives die. Their experience of Victoria's end of life practices has convinced me that neither the medical profession's current practices nor the current laws are adequate.

I am now convinced that the current practices:

1. will result in me having to die alone, and possibly by illegal means;
2. That this may result in a mess that police and health workers will have to clean up; and
3. that unless I take great care, my death may entail the risk of prosecution for my family or friends by a misguided official.

Those prospects are all completely unacceptable to me.

The origins of my concern about options available to me to end my life

My misgiving about end of life options in Victoria began after I signed all the documents provided by the Victorian organisation *Dying with Dignity* in 2001. I signed them believing that they would give effect to my personal wishes regarding my end of life.

However, my lawyer advised me that those documents only had advisory force. He advised me to do two things: (i) to sign another more enforceable legal document on medical guardianship pertaining to the Medical Treatment Act 1988; (ii) to speak to a doctor to ensure that the doctor would be in a better position to act according to my wishes when necessary. However, when I broached the topic with a doctor he politely, but firmly, explained to me why doctors were quite unable to assist me in any of the ways I might possibly want in the future. The doctor's reasons for rebuffing me were not moral or religious; they were due to the legally treacherous situation in which they had to work on end of life matters.

Alerted to the problems facing doctors, I took more interest in legal and medical impediments to dying with dignity as I watched many friends and relatives die. Almost without exception they died in circumstances that were completely unacceptable to them, as they definitely are to me.

For this submission, I have grouped those deaths in ways that (i) demonstrate the weaknesses in the current legal and medical system in Victoria and (ii) identify policy and procedural actions that might remedy those weaknesses. I have used three groupings.

Group 1. Cases involving terminal illness and unacceptable suffering

I have now seen many cases of dying and suffering individuals who begged for assistance to die painlessly. In almost all cases their wishes were not met by the

current medical and legal system. Furthermore, palliative care was inaccessible in most cases.

As I constantly read of instances overseas where wishes for painless death are met I, instead, have to watch friends here dying from painful diseases, inoperable illnesses such as mesothelioma, cancers, brain tumours, emphysema or bowel obstructions, and terminal conditions about which nothing can be done such as melanoma or motor neuron disease. Each of those deaths is a horror story. I firmly believe that one day those stories will be viewed with the same disbelief we now have for medieval medical practices and nineteenth century treatments for mental illness. Modern medicine can do better in 2015 due to improved capacities for pain relief. This is especially so if it is supported by respect for individual wishes regarding end of life rights.

Therefore, for cases of severe pain and suffering associated with terminal illness, this Committee should (i) identify humane means respecting all wishes for a dignified and painless death and (ii) prescribe suitable legal procedures and safeguards to achieve that goal.

I believe that medical and legal policies and procedures to achieve this are easily identifiable. For example:

My suggestions

1. *The simple policy starting point is the primacy of an individual's wishes regarding their end of life.*
2. *Procedurally, a mentally competent individual's wishes should be respected and registered, hopefully at a central registry similar to that for organ transplants.*
3. *Those wishes should be actionable upon appropriate medical verification.*
4. *Those wishes and all ensuing actions should be enforceable through legislation that also protects and renders immune all responsible authorities acting according to the law.*
5. *Procedurally, that legislation should empower, and require, medical authorities to both (i) respond to an individual's wishes by informing them immediately of all available options for termination, and (ii) then to conduct the termination accordingly.*

Group 2. Cases where unforeseen factors frustrate the exercise of properly prescribed choices.

A related area for the Committee to navigate is when a person has taken every currently available legal and medical step to ensure that their wishes regarding their end of life are known, documented and implementable, yet unforeseen events negate those preparations.

I illustrate this situation by describing the case of "A", a highly educated, cultured, professionally qualified and affluent man born during World War 1. "A" died 11 years after the death of his wife, having had 6 active years before he subsequently fell ill 5 years before his death aged 95. Before and after the death of his wife, "A" had taken every available step to ensure that both their deaths would be painless. He had prepared documents to cover all imaginable contingencies and had sympathetic medical friends. Yet tragedy intervened in his case.

His personal tragedy was a series of severe strokes that immediately diminished his mental competence and, equally rapidly, his physical capacity. Those strokes rendered him quite incapable of responding to the unexpected situation in which he found

himself. He became totally dependent on others. Overwhelmed by vascular dementia he had to endure humiliation and total dependency until progressive organic failure ended his hellish existence. Throughout his life he had always made it clear to family, friends and doctors that he would never accept a situation like the one he subsequently endured.

Unfortunately, such situations are not uncommon. I have seen many other instances where intelligent and motivated individuals have taken every possible legal and medical step to arrange a dignified death, but were frustrated by unforeseen medical events.

For instance, “B” suffered severe asthma for 40 years. Consequently, his heart and lung functions were severely impaired. Over decades “B” made all possible preparations to control his death from those impairments. His partner, doctors and friends were all aware of his documented wishes. Unfortunately, his progressive decline from those impairments was overtaken by an emergency bowel constriction at age 77. He underwent a series of operations in hospital. They all failed. The bowel operations resulted in great pain and suffering, complicated and heightened by his poor lung function. Finally, after some weeks with an open stomach covered in glad-wrap to facilitate more surgical intervention, he took the only option remaining to him in a hospital. He produced a signed refusal of medical treatment. Luckily, the hospital respected his wishes and he was transferred immediately to a palliative care unit. This, he informed me, merely prolonged his suffering and was not satisfactory, although he appreciated the sympathetic care from trained staff and the pain relieving drugs. Nevertheless, he regretted having agreed to go to the hospital for emergency treatment for the bowel problem. Before his death, he told me that his mistake was in not having immediately availed himself of the painless suicide solutions available to him at his home instead of going to hospital.

The Committee must recognise such unfortunate situations, and provide acceptable legal and medical procedures to give effect to clear wishes regarding termination.

In my view the preparations that both “A” and “B” had made provided clear evidence of how each wanted to end life. Furthermore, “B’s” wishes were re-confirmed by his wish for immediate termination rather than prolonged palliative care. This means that such cases should be treated in the same way as those in my first group, that is, according to policies and procedures outlined in my *Suggestions* above.

Once evidence of the wishes of the individual are clear, my second group of cases differs little from my first group. Their right to assistance in their wish for a painless and dignified death should remain the central concern of medical authorities.

Those wishes, confirmed if necessary by consulting relatives or friends, should ensure that end of life termination is available to my second group in just the same way as it should be to my first group.

Group 3. Situations where end of life options are appropriate, but not initiated by the individual’s clear wishes.

I think that the Committee will have to demonstrate some courage to deal properly with a third group of individuals I identify. These are cases where there

is real ignorance about available options for ending one's life painlessly and there is no documented evidence of preparation for that event in the form of clear wishes.

I illustrate the difficulties regarding this third group using a person I call "C".

"C" was born in 1910, and was a self-employed tradesman and small farmer. He was highly independent and as self-sufficient in his life style and habits as possible – a result of his experience of the Depression. This highly domestic lifestyle changed rapidly after his younger wife predeceased him. Subsequently, his life rapidly became more difficult and he died 5 years after his wife at age 84.

Alone in old age, he quickly developed senile dementia and physical debilitation; finally he was admitted to an aged care facility. After an initial period of social enjoyment, his mental and physical deterioration continued very rapidly. It culminated in a broken hip that confined him to bedridden misery. Completely demented, it is a testament to his physical resilience that it took a year of this misery to kill him.

Having minimal education, limited social skills, a domestically confined lifestyle and limited financial means, "C" was always going to have problems navigating end of life options alone. The only option he ever discussed was to use a gun on himself, but age, severe dementia and decreased mobility rendered this sole-recognised option beyond him.

"C's'" attitude to end of life options remains common in males, and not just those of his generation. I have seen similar unrealistic bravado among many relatives and friends of that generation. Only occasionally does it result in effective pre-emptive action. This occurred recently when a friend could not live with family losses from the recent Victorian bushfires – he used the old standby method of a hose from his car exhaust, successfully.

In my view a failure such as "C"s" to declare properly his wishes need not prevent supportive intervention to minimise suffering. I believe his humiliating and painful demise demonstrates massive social cowardice in the guise of a misplaced concern with preserving life; in fact, "C"s" life was meaningless in his condition.

While I commend to the Committee the approach outlined in my *Suggestions* above as short-term goal for all sentient cases, the Committee's long-term aim should also be to educate in order to minimise cases such as "C"s". Having resolved policies and procedures for my groups 1 and 2, the Committee should outline a program to quickly educate all citizens about the new options they should have regarding ending their lives. Guns and exhaust hoses represent bereft social options to such people.

Therefore regarding my 3rd group, the Committee must recognise that all members of the caring community, especially personal physicians, will have to play a more affirmative role in the future to provide suitable options for individuals to die with dignity.

The Committee will have to look to overseas practices to identify more pro-active responses that deal situations such as "C"s".

Also, this Committee will have to identify procedures where families, faced with situations like those of "C", are entitled to approach members of the medical and

caring community when suffering by individuals is without purpose, and termination procedures are appropriate and kindly.

In concluding, I perversely draw some hope from my experience of the appalling legal and medical practices currently regulating end of life in Victoria. For, in recent years proliferating age-care facilities have replaced the home and family-based deaths so common in my youth. Perhaps, after this social experience of packing off demented, ill and bedridden relatives to watch TV incessantly in poorly resourced and badly managed old age homes, society will become more realistic about recognising that there are limits to life, and routinely provide options for death with dignity. Certainly, I see this Committee's work as a step in that enlightened direction.

Appearance

In view of my lack of special expertise in this area I cannot see any purpose in my appearance before the Committee, however I am willing to assist the Committee if requested.

Reg Henry

