Inquiry Name: Inquiry into End of Life Choices

Mrs Ingrid Coles-Rutishauser

SUBMISSION CONTENT:

--

My answer to the question “Are Victorian laws adequately meeting people’s expectations regarding medical options available at the end of life” is a definite NO.
My position is based on the following:

Widespread public support for a change
Prior to the recent Victorian state election the ABC Vote Compass survey found that 76% of voters who took part in the survey agreed with the proposition that: “Terminally ill patients should be able to legally end their own lives with medical assistance”. Moreover this was by far the highest proportion of positive responses for any of the questions in the survey – exceeding that for those in favour of same sex marriage.

Current legislation appears to be at odds with the Charter of Human Rights and Responsibilities Act 2006 by
- infringing a person’s right to freedom of thought, conscience, religion, and belief…
- discriminating against a person’s equality before the law…

since it denies individuals suffering physical and/or mental anguish at the end of their lives, in particular those who are no longer able to take matters into their own hands, the right to choose how they wish to end their lives when life no longer has any meaning for them.

Life belongs to an individual
In our society an individual’s life is not the property of the State or any other institution or person. How would you feel if at the end of your life you are not able to ask for assistance to die a peaceful death surrounded by those you love? Remember, however, when thinking about this that you are privileged persons able to afford end of life care options that are out of the reach of most of the population.

Right to life but not at all costs
Democratic societies such as Australia have become very concerned with the preservation of life. Quite rightly so, because once taken it cannot be restored, but at the same time the cost

to society of protecting life at “all cost” not infrequently also has negative consequences when individuals who have taken the lives of others or contributed indirectly by their activities to the deaths of others are allowed to return to society and repeat the offence. Our objection to the death penalty, however, should not blind us to the fact that for those for whom quality of life no longer exists, death is not a penalty but a much desired release.

Evidence from elsewhere

While I have not conducted any personal research in this area my reading indicates that in those countries and jurisdictions in which the law allows assisted death for terminally ill persons there has been no mad rush to “death”. What the existence of such legislation appears to do is to allay the fears of persons nearing the end of their lives by giving them the certainty of a choice in the event that, for them, life becomes unbearable. Surely a change in the law that enables persons to enjoy life to the full in their last years is highly desirable.

A personal plea

It is often said, and I think quite true, that unless one has experienced the distress and deep anguish that comes from living with a close relative (wife, husband, daughter, son) who has reached the point where for them life is no longer worth living simply does not understand how deeply distressing this is not only for the terminally ill or disabled individual but also for the immediate family. Some, but not all of you, will have had such an experience and will understand. For those who have not yet experienced this trauma I ask you to put yourself in my shoes as I relate my husband’s and my experience.

In my shoes - a real life story

At the start of his 9th decade in 2004 Gerry was an active individual fully capable of looking after himself, still taking an active interest in, and contributing to, his profession in which he had received both national and international awards for his dedication and contributions to improvements in the working environment and in the development of standards to protect workers health and safety. In the course of his work he had acquired a degree of hearing loss and at the age of 71 had been fitted with a hearing aid for his right ear.

All his life he had taken regular exercise in particular swimming, walking and sailing. He had never smoked and during all the time that I have known him, has only ever consumed alcohol in moderation.

Shortly after the beginning of his 9th decade he started to have problems with pain in his ankles on walking due to osteoarthritis. After trying all available treatments he was offered only the option of ‘fusion’ of the ankle joint to reduce the pain. This he did not want to undertake because it would affect his ability to swim, an activity which he was still able to enjoy without pain. At the age of 83 he developed atrial flutter which was treated initially with medication and later with a radio frequency catheter ablation. After this he was left with atrial fibrillation and an irregular heartbeat but no further cardiac events.

Despite the pain in his ankles he continued to try and take some exercise by walking as well as swimming but sadly had to give up sailing because he no longer considered it sensible for him to take charge of a boat due to the instability resulting from the ankle pain. This was a great blow to him as sailing had been a lifelong joy and relaxation for him. At this time Gerry also became concerned about his failing memory but after a CT scan and examination by an appropriate consultant was told that he definitely did not have Alzheimer's but simply, what the consultant called age related cognitive decline.

Early in 2010 he was found to have wet macular degeneration in his left eye and this was treated with Lucentis but while this stabilised the condition he had permanently lost most of his central vision in this eye with consequent impairment of his ability to see as clearly as before. At the end of 2010 he was also found to have severe sleep apnoea and treatment for this was commenced, but although the number of hypoxic events decreased markedly there was no resultant improvement in the constant tiredness he felt and for which no specific cause had been found. At about the same time he had a second hearing aid fitted as his hearing had deteriorated further to the point where he found it difficult to participate fully in meetings and social events or to be able to follow radio and television programs at home.

To this point one could say that Gerry's story is simply one of changes in overall health and physical ability to be expected with advancing years and that if anything he had fared better than most in the process and should be thankful rather than despondent. Had he died at about this time he would have had a good and fulfilling life while still being largely independent.

However that is not what happened. In an attempt to establish if there was any organic cause, other than advancing years, for his overall feeling of overwhelming tiredness and lack of energy Gerry was admitted in February 2011 to a Melbourne hospital for a number of intensive investigations none of which proved to show evidence of a any major abnormality. Probably the most relevant finding, on MRI investigation of the brain, was evidence consistent with widespread small vessel ischaemic change.

The failure of these investigations to find anything that could be done to improve his condition probably marked the beginning of a more negative attitude to life. This was in no way helped by being given advice, although it was no doubt well intended, about stimulating his brain by various means to stop further memory loss and to take more exercise and engage more in social activities to improve what health professionals called his depression. Inevitably a range of anti-depressants was tried with no observable effect except an increasing sense of frustration. Nevertheless Gerry continued to swim two to three times a week and to attend regularly meetings of Probus and his Lodge, with the help of transport provided by others. The enjoyment he had formerly derived from these activities, however, became less and less as both his hearing and his eyesight worsened and the fatigue induced by the strain of not being able to hear and see clearly increased during 2011 and 2012.

Early in 2013 his cardiologist decided that a pacemaker would improve matters and one was fitted at the end of February 2013 with every expectation of a successful outcome and an increased level of energy and feeling of wellbeing. Neither of these eventuated and inevitably added to his increased level of frustration. He was advised not to swim for two months after the operation and by the end of the two months he had lost not only the energy but also the willpower required to battle on against the odds. He now started to say that he wished that he were dead and that he had died during the insertion of the pacemaker. Later that year he took an overdose of Lasix in the belief that these were sleeping pills and on Christmas Eve 2013 he took an overdose of sleeping pills clearly in the hope that this act would end his life and spare his wife and family any further distress on his behalf.

The only result of this desperate attempt to get out of his hopeless situation was a short hospital admission and a two month stay in an aged care facility. He was exceedingly unhappy throughout and despite assurances from staff that he would settle, his wife and son and daughter both of whom who came to visit from the United Kingdom saw no signs that this was likely and so arrangements were made to look after him at home for as long as possible.

In the absence of any family members in Australia, other than a nephew in Perth WA, his wife took on the responsibility of sole carer, despite advice from health professionals to consider her own health and wellbeing. It was only too clear to her that the level of personal care that he could be given in an institutional setting was far from that which she could give him at home as long as she was physically and mentally able to do so. It was not easy from the beginning, because soon after he came home it became evident that his eyesight had deteriorated further while in the aged care facility and that he now also had wet macular degeneration in his right eye. It became obvious that he could now longer read any of his books or journals that had previously been a great solace to him once he had become useless for anything else. A talking book player has helped but because his short term memory had also deteriorated markedly since his admission to hospital at the end of 2013 he now needs help to operate this and other devices such as his lifting chair, the telephone or radio or even an alarm button to call for help. While Gerry has needed help with showering for some time, because of the effort involved, he now also has to suffer the indignity of help with toileting and incontinence. In short he has in the last few months completely lost his independence and can see no improvement in his situation except by death at the earliest available opportunity. Medical and allied health professionals have not been slow to provide essentially useless advice, for example that Gerry needs to reconcile himself with his situation and make every effort to take more exercise and participate in social activities outside the home to improve his lot, but are not in a position to provide the help that Gerry wants.

What Gerry, now in his 10th decade, cannot understand is how it is possible that he and others like him do not have the right to choose a peaceful death at a time of their choosing. While his short term memory is very poor he has not lost his mind and it is his mental anguish that is so painful for him and his family. Unlike physical pain it is not easy to quantify, nor treat. It goes largely unseen except by those close to the individual who experiences it.

Gerry does not wish to make an end of life choice for others, unlike those who have the power to give individuals this choice but who have so far refused to do so on the basis of vague beliefs rather than factual evidence and with little consideration for the plight of the individuals whose rights are currently infringed by the current legal situation. Not unreasonably he believes that those who have the power would see things differently if they themselves were in his position.

In March 2015 Gerry’s wife very reluctantly had to admit that she could no longer provide 24hr -7 day a week care for him without help, since the cost of in home care at a minimum of $3,500 per week is simply unaffordable by the average Australian in retirement. The only other option, when there are no relatives to help, is admission to an aged care facility which is the very last thing that most elderly Australians want. It is in no way comparable with care at home by family members. The staffing, even in accredited facilities, is woefully inadequate for residents like Gerry who have completely lost their independence and have to rely on help with absolutely everything. More often than not, the help needed is not readily available and when it comes often impersonal and given without obvious empathy.

What sort of life is this? For Gerry the situation, at best is bleak and at times intolerable. For his wife it is a constant source of worry if not mental anguish. What is to be gained for people near the end of their life, who have completely lost their independence and have no hope of regaining it, in denying them the help of others to effect their wish for a quick and peaceful end in the presence of family members? How long must they endure their incurable distress?

This is inhumane, if not an immoral state of affairs that needs to be rectified as soon as possible if more and more elderly individuals are not to live in fear of what they may have to endure at the end of their life rather than to live their remaining years secure in the knowledge that should life become intolerable they have the legal right to ask that they be helped to a peaceful conclusion at a time of their choice.

--

File1:

File2:

File3: