

SUBMISSION TO PARLIAMENT OF VICTORIA

INQUIRY INTO END OF LIFE CHOICES

My mother died with a brain tumour 37 years ago.. She believed in Voluntary Euthanasia and an individuals' right to demand that their wishes should be considered and acted upon, when stating that they would rather die than live in a state where they could not communicate, recognise loved ones, or lead an independent life or, if terminally ill, were subject to intolerable levels of pain and discomfort/or unwanted surgical and medical treatment, in an attempt to keep them alive, when death was inevitable.

My mother's death happened exactly as she would not have wanted.. She had always asked that we never permit brain surgery, yet due to the circumstances, when she collapsed (undiagnosed) and my sister and I were told that it was likely a cerebral haemorrhage and that if the pressure was released she would be able to lead a "normal" life we agreed. My father was not available and we didn't want to make the alternate decision for him. She woke, recognised family, and 24 hrs later was in a vegetative state. It was 6 months before she actually died and in that time, returned to her home town, she had the indignity of all she hated in the hospital where she had been a Board member, until death finally came.

I am now 75 years of age.

I believe in euthanasia but nothing has changed. In all these years although I have an "Advanced Directive and "Enduring Power of Attorney(medical treatment), I am not convinced that these documents protect me from unwished for medical intervention, let alone assistance to die if circumstances logically dictate that course of action.

I have recently seen one friend, younger than me, more intellectual than me, succumb to alzheimers and is now in a locked ward in a nursing home and aggressive. Another with a terminal brain tumour, operated on and now paralysed, in a nursing home, sometimes seemingly aware of the "prison" he is in, unable to do anything for himself or communicate. These are illustrations of the predicaments many elderly people are finding themselves in.

Many of my aged counterparts agree with euthanasia. Most are horrified at the idea of nursing home care – no matter how good it is. Most would decline intrusive surgery or medical treatment as we accept the fact that death is inevitable, and having lived a good life, would rather the money be spent on keeping other people alive - be spent on medical research, to help those with a full life ahead of them -babies, children, young families to have the medical treatment they need and deserve.

It is vital that there is discussion about death in a more open manner. If we have a choice, then when and how we are to die. What constitutes ridiculous expenditure keeping someone alive who would much rather be dead. Ask the hard questions. Get some honest answers.

Make Advance Directives legal and binding. Ensure hospitals admitting patients over 70 have these directives and follow them. Train medical staff to be more accepting of death, rather than at all costs striving to keep people alive.

Surgeons should be open and ruthlessly honest about the possible consequences of surgery and admit when no surgery or medical treatment would be the kinder more gentle option,.

Some people want to be kept alive at all costs – but at what stage is “life” just a mockery of the word. Palliative care is a great thing, but again not if it becomes a lengthened process of death.

I have had a sub-dural or sub arachnoid haemorrhage, I have atrial fibrillation, I have had a hip replacement. I have already used up a lot of public hospital funds. My body is crumbling and I wish this old body to ease its way to an inevitable death with as much grace as possible. I would refuse any intrusive surgery from now on, I absolutely dread another stroke which is not fatal, and leaves my family watching a miserable decline and my humiliation being kept alive in a nursing home which they know I would consider a living hell.

Politicians talk about the cost of the ageing population, pensions, medical care etc etc. The burden on the younger generations. It is a ludicrous situation, we don't want to be a burden, we don't want medical interventions, we don't want to spend years in a nursing home at taxpayers expense.

The alternative? Help us to access euthanasia. Help us to make sure that medical directives are followed and that we can exit this life with some dignity, love and compassion.

No one has the right to decide that I cannot die when the time is right for me.

Suicide can be ugly, painful, difficult for the family, lonely and appalling for those who discover it.

If you don't get on with the dialogue, if you don't keep a conversation about end of life going and then make some common sense decisions - how many more years and generations will pass – dollars wasted and misery extended ?

I hope I get to choose when I die – I love my family- I don't want my death to be agonising for us all.

Please – we need your help!!

TO WHOM IT MAY CONCERN

The following values may assist my health care providers and family to understand why I choose to make the advance directives which follow:

1. I want to leave good memories to my loved ones.
2. I want to retain some dignity when I can no longer speak for myself
3. I want to be treated with respect
4. I want to experience a comfortable dying process
5. I am not afraid of death and believe I have already lived a full and fruitful life therefore do not wish to be kept alive if my brain function is reduced.
6. I wish to contribute to science, research and my fellow man and therefore am a possible organ donor.

I have had an advance directive for over 10 years and my views have not changed. My mother died with a brain tumour and was in a vegetative state for some months. I do not wish my family to endure seeing me in a similar state for any length of time. My idea of quality of life is to recognize and converse with family and friends and be independent and clear thinking.

My family members are well aware of my intentions and agree to carry out my wishes.

Please see that these directives are carried out on my behalf.

Signed

Date

Gillian Christine Hughes

Witness:

Advance directive

TO MY FAMILY, MY PHYSICIAN AND ALL OTHER PERSONS CONCERNED

This directive is made by me

of

at a time when I am of sound mind and after careful consideration.

I declare that if at any time the following circumstances exist, namely

- a) I suffer from one or more of the conditions mentioned in the schedule (see below)
- b) I have become unable to participate effectively in decisions about my medical care
- c) And, two independent physicians (one a consultant) are of the opinion that I am unlikely to recover from illness or impairment involving severe distress and/or **INCAPACITY FOR RATIONAL EXISTENCE.**

Then and in those circumstances my directions are as follows:

- 1. That I am not to be subjected to any medical or surgical intervention or treatment aimed at prolonging or sustaining my life,
- 2. That any distressing symptoms (including any caused by lack of food or fluid) are to be fully controlled by appropriate analgesic or other treatment, even though that treatment may shorten my life.

I consent to anything proposed to be done or omitted in compliance with the directions expressed above and absolve my medical attendants from any civil liability arising out of such acts or omissions.

I wish it to be understood that I fear degeneration and indignity far more than I fear death. I ask my medical attendants to bear this statement in mind when considering what my intentions would be in any uncertain situation.

This directive should be taken to represent my continuing direction

SCHEDULE

- A. Severe and lasting brain damage due to injury, stroke, disease, CPR or any other cause
- B. Advanced degenerative disease of the nervous system
- C. Senile or pre-senile dementia, whether Alzheimer's, multi infarct or other cause
- D. Advanced disseminated malignant disease
- E. Severe immune deficiency
- F. Any other condition of comparable gravity

Signed by me

this day of in the presence of