



2 October 2017

Submission to Joint Select Committee on End of Life Choices

Dear Joint Select Committee,

I attach my submission to the Committee. I urge the members to accept the suggestions I have put forward.

Yours sincerely

B. Buchanan.

Submission to the Joint Select Committee on End of Life Choices
in respect of Advanced Health Directives

I request the Joint Select Committee:

- 1. to clarify and strengthen the 'rules' in respect of Advanced Health Directives and specifically to*
- 2. to make provision for an inexpensive and readily accessible inquiry and review should a care provider or medical practitioner fail to adhere to the previously expressed wishes of a person set out in a properly completed and signed Advanced Health Directive (hereinafter AHD).*
- 3. Provide for such penalty or penalties for failing to adhere to an AHD as will deter persons from any such dereliction of duty.*

Basis for Submission.

My wife was diagnosed with an incurable progressive neurological illness, the principal effect of which was that she had progressive muscular weakness, resulting over time in an inability to walk, move, talk and swallow. Her chest muscles were affected also, with decreasing ability to draw breath, making pneumonia probable.

My wife was both a Registered Nurse and Registered Midwife and had worked in hospitals, medical private practice and as a Health Educator for over twenty years. I have a Masters degree, an ordinary degree and Post Graduate Diploma.

I state the above 'qualifications' simply to illustrate that the ability of my wife and I to grasp of the facts of my wife's illness, its progress and

outcome was not clouded by any lack of intellectual competence or misunderstanding.

My wife completed an AHD with her General Practitioner. I was present. When provision was entered for 'no action' in the event of pneumonia, my wife specifically mentioned that she hoped she would contract pneumonia, as it results in a painless death.

Subsequently I, my wife's carer, became unwell and perforce she was placed in an aged care facility. The aged care facility was given a copy of my wife's AHD: subsequently I went through it carefully with the RN in charge of my wife's care.

Early in her stay at the care facility my wife was asked if she ever fell out of bed. She had, partially, twice. The aged care facility promptly requested that she sign a document allowing the aged care facility to raise the side bed rails at any time it appeared necessary to prevent such a fall. It was explained that accusations of 'restraint' had been made against facilities that did not have a prior signature. My wife signed willingly.

This legal pedantry contrasted starkly with that which later followed.

My wife became unwell. The aged care facility called a medical practitioner who diagnosed pneumonia. It was a weekend and although the on-call practitioner may not have been aware of the provisions of my wife's AHD, the care facility certainly was aware and permitted antibiotic to be administered, resulting in my wife's recovery from the pneumonia. The next day she spoke briefly for the last time — three words.

Thereafter my wife declined rapidly, suffering rashes and bed-sores, inability to speak and severe discomfort (relieved by painful morphia injections). She died fourteen days after having been 'saved', during thirteen days of which she suffered pain, indignity and distress. I also was affected.

Subsequently I spoke to the GP with whom my wife had completed her AHD and asked why my wife's wishes had not been followed. He stated that such failure to adhere to the provisions of an AHD was 'common', (my emphasis), whenever the practitioner concerned thought that a period of "reasonable life" might be enjoyed by a patient so saved/resuscitated.

Irrespective of any possible legitimacy of the GP's approach, my wife experienced "reasonable life" for one afternoon only following her being 'saved' from pneumonia. Her sufferings were greatly exacerbated by the failure to comply with her AHD wishes.

On enquiry I was informed that problems in relation to the performance or otherwise of an AHD had to be placed before the High Court. Presumably such a referral would have been costly and I was not mentally ready for such an action immediately following the death of my wife in distressing circumstances.

As a result of the above experiences I wish to suggest the Joint Select Committee report in such manner as will deal adequately with the three points listed at the beginning of this submission.

B. Buchanan.