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Joint Select committee on End of Life Choices
By email to www.parliament.wa.gov.au/eolcc

SUBMISSION ON END OF LIFE CHOICES

Thank you for the opportunity to contribute to this inquiry.

Below please note especially points A to F which are things that I think the Committee should take into account and finally please consider seven points for action. I address only the first and fourth terms of reference.

I am 71, retired, more or less fit and able, and currently attempting to set my affairs in order for this final stage of my life: as my wife says, "Attempting to plan for the unplannable." I do have strong beliefs in the sacredness of all life and our responsibilities to act justly with each other, to be loving and caring and to walk humbly with my god. I do believe in our rights and freedoms to live without harming others and to be free to choose how I depart this wonderful life.

I have no medical or legal qualifications. However I do have my own experiences of the deaths of three people close to me and of people I know.

Advance Health Directive

I acknowledge the role of the WA Parliament in approving AHD's for our State. In consultation with my General Practitioner I have developed an AHD to cover situations in which I am unable to make reasonable judgements in respect of proposed life-prolonging treatments. These situations include suffering from end stage terminal condition, near death incident involving coma, brain death and paralysis. On the other hand I do give consent to certain treatments to palliate my condition even though these treatment might shorten it.

I believe that having an AHD is similar to having a will. It's one of those things that being a responsible member of a family and the community should do so that the loose ends are tied up with as little fuss as possible.

However, there are three problems with my AHD.

1. The AHD covers only situations in which I am unable to make reasonable judgements,
2. My AHD hands the ultimate decision-making to others. I believe that I should be treated with more respect, engaged in the decision before I become incapable and that others should not have to wear the responsibility of final decision-making.
3. Ambulance and Emergency Department staff will be unlikely to know about my AHD and will keep me alive as their duty requires.

In relation to my freedom to choose how my life ends, I believe that

- A. situations in which I am able to make reasonable judgements about my end of life choice should have some legal framework that provides my views at the time with respect
- B. there should be provision for those caring for me to have clear protection from adverse legal consequences of following out my requests.
- C. Emergency workers should be able to know about and respect my wishes rather than follow their procedures regardless.

I learnt something from my father's death. He had smoked from the age of 13, had lived through WW1, the Great Depression, and WW2 as a soldier in difficult situations. At one point he walked from the north of the island of Crete to the south side while under attack from German dive bombers. He suffered from severe emphysema being in the end unable to do much more than walk from the lounge to the bedroom. Having been a proud man, immaculate and fashionable dresser and skilled and artistic sign-writer, in the end he was losing control of his bladder to the extent that the floor beside the bed rotted away. His heart was distended into an almost unrecognisable shape. He lost energy for anything beyond sitting, gazing out the window, attempting to read the daily paper and listen vaguely to the radio. He finally collapsed at home with a violent heart attack. He never spoke to me about his wishes for his end of life but I know that he would have preferred to have more dignity and self-control in his ending, though throughout his life from 1903 to 1988 no one in our circles had ever heard of choices in ending our lives.

- D. There should be wide awareness that respect for the lives of fellow human beings which forms so much of our civil society in relation to health care, education, housing, security, freedom of religion, and so on, should extend logically to respecting the way they wish to end

their lives.

I learnt more from my mother in law's death. Having been a smoker for a while in her 30s and following years of increasing emphysema, her lung capacity was down to 25%. She had been a Registered Nurse, star quiz performer, active and engaged parent and grandparent who read classical English and Australian literature, attended and presented to the University of the Third Age, and knew the names and dates of all the monarchs of England. She spoke often of how distressing it was to read a book or article and find that she could not recall the paragraph she had just read. She would watch television and within ten minutes would be asleep and afterwards was unable to recall anything of the program. To her it was embarrassing and shameful.

She suffered from more and more frequent attacks of pneumonia. After one in which she was admitted to hospital unconscious, administered antibiotics and recovered, she told her sister that this was a trial run. One day she said to me that, since I wasn't a close member of the family, she could talk to me, and that she just wanted to float away.

At the next bout of pneumonia I drove her to hospital. She told the attending doctor that she wasn't going to accept any antibiotics. He took her at her word and had a conversation about what that action would mean. Since she was a nurse who had run a nursing home, she knew exactly what she was asking for. He said that he would have to talk to the family. This happened around her bed and subsequently morphine was commenced. Around this time she spoke one by one to her children and grandchildren and to one special nephew. She spoke with dignity and intelligence telling them not to cry for her but get on with their own lives. Within two days she passed away without suffering or distress – I was present when she died. It was a beautiful death, full of dignity and connection with those she loved. Her family were able say goodbye to her when she was, certainly not at her best, but at least in a dignified, calm and coherent state – in fact the way I want my loved ones to remember me at my end.

E. People facing death along with a quality of life that is humiliating and deeply distressing should not have to do trial runs or prepare to resist the wishes of medical staff in order to choose how to leave their lives in the way they wish and at the time they choose.

My last experience with death involves my 15 month old grandson who died in our lounge after living with a major congenital heart defect which was not corrected in spite of surgery. To witness a baby who, instead of laughing, playing and exploring, was unable to do anything beyond play with my wife's hair let alone with stand, crawl or even sit. His eyes were sad and he had little interest in life. His life and death were sad in ways that the life and death of an elderly person who has lived life to the full cannot be sad. For him it cannot be said as I want to be able to say "When I die, I want all of my life to be used up."

Finally I recount some else's story. It's one that illustrates the inhuman position in which the current laws place people. This person's husband could scarcely breathe or feed himself due to advanced emphysema. He obtained some medication, managed to take it and died at peace attended throughout by his wife. The police attended and told her that she was under investigation, a situation which hovered over her for over a year. An officer asked her why she hadn't gone shopping while her husband died as it would have absolved her of any implication. She was stunned at his lack of empathy and replied, "We've been married for 40+ years. Do you think I'm going to leave him alone particularly now?"

F. Respect for individuals and the unique ways in which they understand and experience their lives, feelings and prospects should be a guiding principle for the Committee. Imposing our beliefs on others is not something that I or in particular members of a Committee entrusted with reporting on end of life choices have any right to do.

Here's what I urge the Committee to consider recommending :

1. The AHD framework might be extended to cover situations where the signatory is able to make reasonable judgements about treatments so that, given acceptable safeguards, carers (both family and medical) are protected against prosecution.
2. In arriving at acceptable safeguards for both AHDs and for End of life choices, it might be useful for the family and medical staff are interviewed and assessed by someone with psychological insight into relationships and motivations, so the whole process is as arms length from the participants. The criteria that such an assessor could used

- might include people's attitudes to the person wishing to die, whether they had conflicts of interest, the quality of their involvement with and support of the person leading up to the meeting, the quality of the interactions within the family.
3. Our faith in our society as just and caring provides a rationale for enabling choice in ending our lives. Just as our society deeply respects and makes provision for people's welfare, needs and wishes in regard to a host of things - parenting, childcare, choice in education, health and health insurance, freedom of religion, pensions, security - so I ask the Committee to take the view that this respect should be extended logically to choices for the ending of life.
 4. Even without an End of Life Choice legislation, such choices are already being made successfully in consultation with medical personnel but this is done without legislative support and protection which imposes unnecessary and inhuman stress on people. End of Life laws should attempt to clarify this situation and ensure that families and workers are protected.
 5. Ironically people are taking measures to end their lives because of what they experience as insufferable distress. I guess we all have the right to do this and by choosing to live unhealthily many are suiciding by degrees. But so often they do it in ways that cause great distress and horror to others, sometimes people they may wish to hurt emotionally but often just public servants driving trains or buses or emergency personnel, leading to these workers suffering PTSD. I do not know what to suggest here but just wish the Committee to acknowledge it as a problem. Whether removing the taboo on death would help people contemplating suicide or not, I do not know either but to bring the topic into ordinary conversations may help some realise the essentially self-centred nature of suicide and the impact of suicide on loved ones.
 6. To deny others the right to choose how to end our lives may reflect our own fear and a denial of the fact of death. Now that private and public conversation has encompassed one of the great taboos - sex, maybe we are now able as a society to engage on the last great taboo - death, or the journey to death. I urge the Committee to reject views that prioritise the continuation of life above everything regardless of the quality of that life and of the suffering that the living are undergoing - both the dying person and those who love that person. I suggest that our ability to embrace our own death and how we

arrive there is a measure of how truly we embrace our own life and the relationships we have with others. For relatives to insist on keeping someone alive against that person's wishes and/or regardless of the suffering that going on living entails, may reflect more their own fear of death.

7. In a similar way our society has long lost direct connection and experience with death. My parents lived in early twentieth century societies in which death happened in the home and was experienced directly. The loved ones washed and dressed the corpse and it lay in the lounge until the funeral. Today death has been removed to hospitals, sanitised, medicated, and outsourced to funeral parlours who apply make up. The committee has a role in enabling our community to achieve a less fearful, more honest and healthy connection with death.

James Mumme

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The Committee invites written submissions that focus on its terms of reference, which in particular require it to:

- • assess the practices currently being utilised within the medical community to assist a person to exercise their preferences for the way they want to manage their end of life when experiencing chronic and/or terminal illnesses, including the role of palliative care;
- • review the current framework of legislation, proposed legislation and other relevant reports and materials in other Australian States and Territories and overseas jurisdictions;
- • consider what type of legislative change may be required, including an examination of any federal laws that may impact such legislation; and
- • examine the role of Advanced Health Directives, Enduring Power of Attorney and Enduring Power of Guardianship laws and the implications for individuals covered by these instruments in any proposed legislation