1 Attachment

5584f6de6f49e-Submission re end of life choices.docx

Inquiry Name: Inquiry into End of Life Choices

Mrs Elaine Roberts

SUBMISSION CONTENT:

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File1: 5584f6de6f49e-Submission re end of life choices.docx

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Submission to the Inquiry into end of life choices

I have just turned 70, however suffer several of chronic health conditions, and the more contact I have with the health system the more apprehensive I become regarding the end of life care that will be available to me. I am very concerned that a culture has evolved in the health care system that patients should be "saved" because the medical profession possesses the technical skill to do so with little regard to quality of life of those patients & whether they wish to continue living.

Recently I spent a few days in hospital following minor surgery & found myself sharing a ward with two ladies in their nineties. Both were profoundly deaf, confined to bed and finding it difficult to cope with the hospital system, its call bells, menu choices etc. Neither were able to read, listen to music or radio or watch TV programs; in other words their quality of life was close to zero. Why were they in hospital? The personnel in their respective care facilities had sent them there because they had pneumonia. Pneumonia is traditionally known as "the old man's friend". I know from personal experience that, when suffering from pneumonia, one is not in pain and really couldn't care less about what happens to one. I believe these ladies should have been permitted a peaceful release from life in the familiar surroundings of their care facility. But, it seems, "the system" does not allow this.

The late Joan Kirner is quoted, in *The Age p30 6/6/15* *Joan Kirners Legacy*, as believing "that the people who are affected by decisions should be part of making them." Accordingly I am grateful the Parliament of Victoria has seen fit to invite submissions from ordinary citizens to the end of life choices inquiry. Clearly your Committee's inquiry cannot change the prevailing medical culture but there are some practical measures that could be legislated for.

Statement of patient choices
There should be a standard format. Presently there are a number of formats for these documents even within a state. Understandably busy emergency department doctors don't take the time to trawl through them to uncover the information related to the present condition of their patient.

A common format should be accepted in all states. Presently each state has their own regulations. A grey nomad would need to complete a statement for each state in case they had a major medical issue during their travels.

The statement at present only applies to existing conditions. It seems to me ridiculous that your basic wishes regarding end of life treatment should be disregarded if a freshly diagnosed condition is the one which threatens to carry you off. It also means each time another health issue emerges one needs to complete a new statement.

Patient choice regarding treatment should be mandated to outweigh medical opinion.
Doctors should be required to take account of patients wishes as expressed in Statements of Choices or by the holder of their Medical power of attorney. This should be the guide for treatment - not the technical skills doctors possess. I am haunted by the circumstances of my mother's death. She was ninety six, living in her own home in a country town, with some assistance with gardening, heavy cleaning & washing, when she suffered a fractured femur as a consequence of a prosthetic hip becoming loose. She was transported to a large regional hospital, Ballarat, for surgery. I spoke to both the surgeon and the anaesthetist prior to this surgery. I told them I was her only child (ie no one else could sue them) and said that I believed her quality of life would never be as good again and that if she died during the surgery it would be a blessing. Her heart did stop during the surgery but the doctors, I suspect with their eye on their insurance premiums rather than their patients welfare, revived her. As they would have known, at her advanced age her bones did not knit, and she spent some months in hospital and then a nursing home. Every six weeks she was taken for an x-ray to check the progress of her broken leg. Eventually she realised that her leg would never heal & this was life from now on. She no longer wanted to live.

Mum was not the only one affected by this display of medical arrogance. I was, as were my husband and our children. I had to watch my mother a private, dignified , elegantly dressed gentlewoman stripped of her privacy, dignity. glasses, hearing aids & in the end the very clothes she so enjoyed wearing. At that time I was in my late fifties, in full time work, with our student children, in their late teens, still living at home. I was fortunate to have a compassionate principal, at the school where I was employed, who allowed me an afternoon off mid week so I could make the 90 minute trip to Ballarat, spend some time with mum & make the return journey. This trip was repeated on the weekend. After some months of this routine, & dealing with all the issues raised by late life care, I was exhausted & found myself nodding off whilst driving back to Melbourne. Reflecting on this I decided I needed to prioritise the welfare of my own family & not risk being smashed up or suffering a premature death in a car accident. Accordingly, I didn't visit mum for what turned out to be the final three weeks of her life.
I have inherited mum's osteo-arthritis & have prosthetic joints. I do not want to die as she did.

Establish a protocol for voluntary euthanasia

Stephen Hawking, who would have had cause to think about death, is quoted *on p 23 The Age 6/6/15* as believing it is "the ultimate indignity to keep someone alive against their wishes".
I agree entirely and would be much relieved to know that I can legally call upon a treating doctor's assistance to end my life & that the doctor would not be liable for any penalties at law. The Victorian Government should frame legislation to allow this. All members of parliament should be given a conscience vote on the issue.

I am bemused that the mores of our society allow us to give our pets a quick & painless exit, when their bodies begin to fail, but deny similar consideration for our human loved ones. Citizens who have a religious or moral objection to such an end of life choice would not have it imposed upon them. But nor should their views circumscribe the choices available to others.

Clearly doctors who have a religious or philosophical objection to participating in this type of end of life care shouldn't be required to provide such assistance BUT they should be required to advertise their opposition to such a practise so patients have the option of choosing another practitioner.

e-health records

I understand that these records are an initiative of the Commonwealth Government but I am alarmed that the present Federal Government is considering defunding this innovative program. State governments could, & should, lobby to ensure the program continues and the following provisions are added.

<u>Statement of choices should be at the very top of every e-health record</u>. I was astonished to find when completing an e-health record with my GP that there is no provision in the format of the e-health record to include the text of a statement of patient choices. My doctor included a note that I had completed a Statement of Choices but my end of life wishes will not be available to paramedics, emergency department doctors etc until a member of my family arrives with a paper copy. This seems rather antediluvian in the computer age & could lead to someone receiving treatment in the interim, such as resuscitation, that they do not wish for.

<u>The holders of the patients Medical Power of Attorney</u> should be identified on the e-health record so their opinion regarding treatment could be taken into account even if they arrived at the emergency department without the piece of paper that proved their bona-fides. It is illogical & impractical to expect that the holders of these documents carry them at all times.

<u>Biometric identification should be part of e-health records.</u> Since it appears we will soon be able to access our bank accounts with a fingerprint or eye scan how much more important is it that these tools should be used to allow paramedics or emergency department doctors to access a patients records, this can be done even if they are unconscious. Surely, at the end of life, access to medical records and patient wishes are more important than access to bank accounts?