Attention:Principal Research Officer
Joint Select Committee on End of Life Choices
Legislative Assembly
Parliament House .
Perth WA 6000
22nd October 2017

Ms Amber-Jade Sanderson MLA
Chair of Joint Select Committee on End of Life Choices.

Dear Ms Sanderson,
Thank for considering my submission on End of Life choice. I am a believer in Christian values ,a nurse of many years and believe I have seen enough death and disease to realise,its time for reconsideration for peoples right to choose death,in a peaceful considered manner,although we have a advanced medical service in this country.

Terms of Reference

(a) In the Hospital, the Patient has the choice of having a current Advanced Health Directive(AHD) and hopefully have a strong advocate to back up their directive. There is sometimes a pressure to accept treatments.

On admission paperwork to a hospital, there is a box to tick if Patient has a AHD but no further action takes place.

The health team may suggest a plan of treatment, aimed at prolonging life and comfort, no matter the quality of life, at that point, and the patient is given a opportunity to ask questions, no other assistance is offered to the patient to express a plan for their end of life management. Occasionally the patient may be asked if they want resuscitation,with minimal explanation or education.

Any one asking for a “end to their life” is discouraged from further discussion.
Patients in Nursing Homes repeatedly state “let me die”,this statement is not discussed in any way even if the patient is considered to have capacity. Nurses feel obliged to reassure the patient they are loved because we know there is no other choice to offer,refusing food is their only option,they are not “terminal”
I have heard a very lovely General Practitioner (GP) say “not dying is the problem” Poly pathology of the aged or as result of chronic conditions is particularly sad and difficult for all concerned - poor quality of life but no life ending pathology. Quality of life is a individual concept,medical professional respect that, and care for people in all states of health. To suggest that Doctors will be encouraging people to end their life in the case of the elderly, is insulting to the medical profession as a whole. Elderly people do ask for a end of life ,without any encouragement from anyone,I have heard it many times. My own GP agrees,having a end of life option in place, is a good plan.

Palliation at the very end stage of life is the only option,and this is only offered /discussed with family first and then the patient, only when there is very limited quality of life and/or a disease process is very advanced,with no expectation of recovery.

It is unlawful to assist a person to die,so Palliation is sedation,and symptom control if possible,while the patient dies slowly of their disease, assisted by dehydration and starvation.

In 2008 there was a case of a competent man ,normal mental health, confirmed by a Psychiatrist. He was 49years,a complete quadriplegic,in a facility for years, he had asked 23 times to stop his tube feeding so he could die. With assistance of his strong advocate friend ,He took his request to court and won the right to die. Palliation for 6 days. (Rossiter/ Brightwater./Justice Martin 2008)

Was there a conflict of interest here? This man had no autonomy and no physical capacity to act for himself but was not listened to even though he had mental capacity,the facility was unclear on their legal standing,were they assisting his dying if feeding was not continued.? There will be cases like this ,and of courses safeguards should be in place-for the patient,who is the one suffering and for the medical profession.

Surely,we in WA ,could have compassion along with other enlightened countries which have safe and functioning Voluntary Euthanasia laws.

RECOMMENDATION :

Medical practices have a "Care Plan" as part of the visit to the GP, AHD/end of life planning could be part of that plan,for any age.

GP s could give a reminder,to update, just as a reminder to have a screening Pap.test is sent.

AHD could be available in Pharmacies,GP practices , any Health facility. Not all older people are happily computer able,so make ADH more easily available.

(b) Current Legislation,does not allow assisting people to die. This needs review to prevent some very inhumane deaths in homes and health facilities.

Having a history of seeing loved ones die in very unsatisfactory situations, causes distrust of the medical profession and uncertainty about our end of life.

People end their own lives ,that is not illegal. Wanting to be with your loved one when they plan a good and gentle death for themselves is fraught with fear of prosecution . This seems cruel and unnecessary use of police time,Police must investigate a unexpected and even a expected death, if the Doctor will not sign a death certificate or is not available to sign certificate.

If the Doctor suspects the person has ended their own life, the Doctor has no choice but to write suicide, even though death from disease was imminent . Another category could be added to the reflect death as a action of Voluntary Euthanasia .Written notes stating this, are often left by the person, in a effort to protect their loved ones from suspicion of helping and the stigma of Suicide on a death certificate .

Social stigma of Suicide does not sit well with older people,who just want to avoid inevitable and unpleasant decline in health and quality of their life and dignity. We need not be afraid that people are going to rush to their deaths even if the law is changed, people generally want to live, life has t

be very grim for a person to seek relief in death. As we stand now, people are seeking drugs from overseas,where quality is unknown and importation may be illegal . Again increasing Police workload.

Wanting to die when quality of life is diminished or rapidly diminishing,is not a mental health issue, its a acceptance of life ending . People are realising that medical treatment cannot always add quality to life. The statement of some ethicists that older people want to die because they are lonely is incorrect in my experience.
Youth suicide is tragic, a choice of Voluntary Euthanasia is a well considered choice of the older person, who are competent and aware that things won't improve with further ageing.

RECOMMENDATION:
Change laws to allow a clear option to request end of life assistance from a Doctor,or other authority for example-set up a Government controlled register to apply for end of life drugs.

Appropriate safeguards- Request is from patient only,voluntary and repeated with suitable interval. Person requesting must have serious life limiting or terminal illness or have unacceptable quality of health and be older age group.
Exceptions could be put to a panel of doctors,in cases like Rossiter,who request and are in exceptional circumstances.
Person may have option to administer own drugs at place and time of their choice , with loved ones present.
Make a advocate for the patient be responsible for the drugs safe storage .

Change the Legal register to allow death to be registered as Voluntary assisted death, or Rational Suicide.

(d) Some people still are unaware of AHD and its legal value,some place it with their will.

People are concerned with the wording and not the concept of letting the health teams what their wishes are. There is absence of a universal method of alerting people to the existence of a AHD,although this may change with the event of electronic medical records.

Health professionals can override AHD if it appears the a attempt to end life has occurred. This aspect of AHD needs review.
Doctors like to confirm the validity of the ADH with family members. Families don’t always agree with each other or with the AHD .Refusing treatment is not easy,sometimes pressure is exerted by medical staff or family.

RECOMMENDATION:

Review Advanced Health Directive with the view to allow for End of life action, not just palliative care.

Concluding comments:

Medicine has impacted on every stage of life, from pre conception and beyond. When end of life comes ,we hesitate,expecting some miracle . In 45 years of Nursing I have not seen any miracles,I have seen a lot of good medicine and some very unpleasant death which could have be better for the patient if a assisted death or assisted voluntary death was provided or allowed to be prescribed. Safeguards are in place and should continue to be .

Compassion and kindness should prevail to the end as well,when a person is most in need and requesting a end. Religious beliefs are be accommodated currently and after death also,this will continue, no one is asking a person of any religious to participate, in assisted end of life or voluntary euthanasia. I just want to have a choice and not be dictated to by another person.

I would be happy to give evidence in person. Confidentiality requirement prevents me from providing documents or names.

Yours sincerely,

Carol O'Neil
RN.RM