EOLC Sub 511
Rec'd 22/10/2017

22 October 2017

Dear members of the Joint Select Committee on End of Life Choices,

I am a Clinical Registered Nurse specializing in Palliative Care working in a large rural centre in Western Australia. I am part of the Palliative Care Team working for WA Country Health Services, and I also work in an inpatient unit which is licenced as a private hospital in the town. I have been involved in Palliative Care for the past 16 years and am very passionate that the provision of care is done well.

When I began working in Palliative Care it was seen as a subacute form of health service, more akin to aged care than acute medical care. Over the years it has grown as a medical specialty to the point where now it is indeed a specialized field of medicine. Palliative Care is multi-faceted and focusses on providing holistic care encompassing relief of physical, emotional and spiritual symptoms for both the patient and their loved ones. It concentrates on allowing the person to live well in the place where the person wishes to be for as long as possible. It encourages the person to have a meaningful, or purposeful, journey through life.

A study of various cultures and religions around the world will reveal that the Western culture which largely embraces hedonism does not do difficult things well and that instant gratification and instant solutions are important to them. A good life is synonymous with freedom from suffering and pain. Other cultures such as those based on Hinduism, Islam, or Christianity embrace suffering, embrace difficulties and learn very valuable lessons from them. Our humanitarian culture says we relieve suffering as much as possible and it is everyone's right to be happy. It is my firm belief that there is purpose and value in all that happens while we are alive. Not just the good times but also the difficult times and I have seen this many times in the course of my work.

People are a lot more open when they ask about euthanasia now than even five years ago. Then they would ask in a very obscure way whereas now they will use the word euthanasia and ask the palliative care nurse or doctor directly for a way out of this world. However when exploring the reasons behind the request, the answer is usually fear. Patients, and families, are fearful of the journey ahead which is unknown. Especially in rural areas, extended family support can be minimal as children have moved away to the cities, interstate or overseas. People are afraid they will be a burden on their loved ones or they will end up in a nursing home. People are frightened they will be in uncontrollable pain, or they will lose their dignity. At basis, people feel unsupported by a society that does not value the sick or aged.

Another thing to note is that discussion of euthanasia often occurs early in a patient's journey with an incurable illness when the patient asks because they are overwhelmed with what is happening to them, or it occurs right near the end and then it is not the patient but the families that ask because they can't deal with supporting, or watching, their loved ones deteriorate.

As I have said, Palliative Care has come a very long way in the last 10-15 years. Data is being collected Australia wide with input from a very large number of palliative care services. This data is being collected by the Palliative Care Outcomes Collaberative (PCOC) and is mapping amongst other things palliative care provision, symptom occurrence and distress experienced, and the type of people requiring palliative care. There are many gaps in the provision of palliative care especially in the rural areas. As an example, here in our local area there is a very low percentage of patients who die in their own homes surrounded by their loved ones in a place where they love to be. We are well below the national benchmark. This is in part because the local community nursing service contracted by WA Country Health Services to provide 24hr palliative care has been unable to deliver this service and now runs a generalist nursing service 12 hours of

each day. They do not have palliative trained registered nurses on staff and do not have their own palliative trained medical staff either. Palliative care patients, often physically weak, need to make regular treks to Perth to access PET scans, oncologists, radiation therapy and some chemotherapies. It gets too much for them and they give up on the medical system opting to stay at home as this is more important to them at this stage of their life. Rural communities struggle to find trained palliative nurses and doctors with the expertise to help those in need.

As for end of life choices, people do have choices. Much education and research is being done presently regarding the use of Advanced Health Directives, Advanced Care Plans, Goals of Care documents and appointment of Enduring Power of Guardianship. Here in our local area these documents are standard use in the care of our patients. In fact in our local community hospice I have just developed a Goals of Care document which gives people choices of different levels of care which they would like to receive whilst in hospice. We encourage the patients to fill them in so that they make known to all professional staff, as well as their loved ones, their wishes regarding their care and place of death. They are proving very helpful in the delivery of care as well as in giving the families peace with the care being given to their loved ones. We do not use "NFR or DNR" (not for resuscitation or do not resuscitate) forms as these were an all or nothing document. The patient either opted for all treatment or no treatment. Patients can now choose levels of care required and they are informed choices as they are discussed with their medical team before signing.

I humbly submit, and ask you to consider, <u>not</u> recommending the legalization of euthanasia and assisted suicide. You only need to look at other countries where this has occurred to see how quickly society then slides backward, and the aged, those who suffer chronic illnesses, and disabilities, become very vulnerable when they need protecting. Anyone that is a financial burden on society and governments are at risk. Life is precious, only occurs once (which is often realized only once a loved one is gone), and all people are valuable.

Instead **I strongly ask you to recommend to the government**:

-all life is valuable until the moment of death

-24hr palliative care which relieves symptoms is a basic right to all people in Western Australia regardless of their location

-medical and nursing staff need to be protected by the law. Supplying or administering euthanasia is contrary to our philosophy of relieving suffering and preserving life.

-funding is given to train medical, nursing, and allied health practitioners in palliative care

-all palliative care medications and treatments to alleviate symptoms which cause distress are covered by the Pharmaceutical Benefits Scheme (e.g. Ondansetron for nausea and Midazolam for anxiety are not and both are commonly used)

-each regional area has its own Palliative Care Team consisting of a Palliative Care Physician, medical staff, Palliative Care Nurses, allied health staff.

-funding is given to educate the general public on the support services available to enable their loved ones to live a fulfilled life regardless of health status.

Personally I hold very deep Christian principles which determine my actions. I am very passionate that every life is precious and valuable. I have seen many families come together around the dying person's

bedside, united in love and care. Just as the birth of a child is very special, so is the death of a person. It is a privilege to care for people at either end of life. It is a real privilege to guide them through a difficult journey, to allay their fears, to help them see meaning in a time when they are vulnerable and when time is not in their control. If euthanasia is legalized and hospices become a place of killing rather than dying I will need to leave a profession I love dearly and hope to be in for many years. I plead for my patients, I plead for my families, and I plead for the medical staff involved.

Thank you for reading and taking note of my submission. If I can be of further assistance, it would be my pleasure.

Mrs Ingrid Plug