EOLC Sub 630
Rec'd 23/10/2017

Submission by the Western Australian Palliative Medicine Specialist Group (WAPMSG)

The Western Australian Medical Specialist Group (WAPMSG) consists of 27 actively practising Palliative Care Consultants in Western Australia. We are all either Fellows of the College of Physicians specialising in Palliative Care or Fellows of the Chapter of Palliative Medicine of the College of Physicians. Between us we have several hundred years of experience in end of life care and have tended to thousands of patients with life limiting illnesses. Several of us have practised in this discipline for more than 20 years. We perceive widespread misunderstanding and confusion in our community, even in the medical profession, about Palliative Care and the relationship with euthanasia/Patient Assisted Suicide (PAS).

We wish to state categorically:

1. Euthanasia and Physician Assisted Suicide (PAS) is not part of the practice of Palliative Care in Western Australia.

2. Palliative Care and Euthanasia/PAS are two completely distinct practices and should remain as such.

3. Any consideration of end of life choices should have the provision of adequate palliative care services as a fundamental foundation. These services are not universally available throughout Western Australia.

   We regularly encounter patients/families who decline or are reluctant to engage Palliative Care because they think we practise euthanasia or intend to shorten their lives. It takes considerable time and expertise to allay their fears and then we are able to address their needs, their physical symptoms and their psychosocial/spiritual care.

   We are very concerned that if the two practices are associated that there will be many patients who will miss out on optimal symptom control because of their reluctance to have a palliative care assessment. This could result in many patients dying in distressing circumstances.

4. Referral to a Palliative Care Service does not mean an end to active treatment. The Palliative Care Team works in cooperation with the medical oncologists, radiation oncologists, surgeons, neurologists and other clinicians to achieve the best outcome for the patient and their carers'. Appropriate treatment options are considered with the patient/carer having the final decision as to how to proceed.

5. Care of patients in their last days/weeks of their life forms only a portion of our work.

   Many of our patients with advanced disease are under our care for many months while undergoing active, life prolonging therapy such as chemotherapy and radiation therapy.

This Parliamentary Committee has been established to study End of Life issues.

Terms of Reference:

a) 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 illness:

At present, patients can only be referred by either the treating doctor or by their General Practitioner (GP).

If the doctors involved do not recognise the need for Palliative Care or how to access it, their patient could be disadvantaged with suboptimal symptom control and end of life care.

There is inequity of access to Palliative Care in the Regional areas, some secondary hospitals and Aged Care Facilities

Palliative Care is delivered by a team of specialist nurses and doctors and allied health practitioners e.g. social workers, occupational therapists, physiotherapists, pharmacists, dieticians and speech pathologists, pastoral care workers, psychologists, psychiatrists, counsellors and volunteers. Having access to all members ensures a comprehensive, holistic care program.

The team involves the patient and family in decision making. This often involves meeting formally with the patient and family members to discuss the following issues:

i. The concept of patient centred and patient directed care by the professional team.

ii. The need for assessment by allied health. For example, social work will ensure that the patient and family can access all available assistance financially and practically.

iii. Medications currently used for symptom control are reviewed, their intended effects and possible side effects are discussed.

iv. Options for active treatment are reviewed. What is burdensome for one patient may not be for another. Patients are supported to refuse active management if it is deemed burdensome.

v. How the patient views dignity and quality of life is acknowledged. This is very individualistic and subjective. It needs to be explored sensitively and incorporated into their ongoing end of life plan.

vi. The location of care needs to be determined. While the patient's/family's preference is acknowledged, the team needs to assess what additional services should be organized if home is the preferred option, and what is the contingency plan if home care cannot be sustained.

vii. Where they wish to spend their last days.

viii. Their goals and wishes, (a "bucket list") and how we can assist them to fulfil these wishes.

ix. Relevant paperwork, such as Advance Health Directives, Wills, Enduring power of Attorney.

x. Our care continues beyond the death of the patient to provide care for the bereaved family.

These meetings are held as often as needed. Clear communication, sensitively given is the aim of these meetings.

By providing information, knowledge and support, we empower the patient to make the choices that he or she finds acceptable.

In the terminal phase, the team answers questions from the family about the process of dying and how we will manage it. We make plans which take into account the patient's choices e.g. whether they prefer to die at home, in a hospice or a hospital. Some patients like to be fully asleep while others prefer to be alert, interacting with their family, even if this causes some discomfort.

We empower our patients to make choices and we tailor their care accordingly.

b) Review the current framework of legislation, proposed legislation and other relevant reports and materials in other Australian states and territories and overseas Jurisdictions

The current legislation in Western Australia permits doctors to use whatever medication is necessary to manage a patient's illnesses and symptoms as long as there is no intention to hasten death.

Some doctors argue that the Law is unclear and consequently, they feel vulnerable to prosecution. Others argue that the law is open to abuse.

There is ignorance even in medical circles about the uses and limitations of opioids and benzodiazepines. For example, the continuous subcutaneous infusion of an opioid with or without a benzodiazepine is often blamed for the death of a patient.

Some doctors and nurses label this as "slow euthanasia". Nothing could be further from the truth. These subcutaneous infusions are started when the patient is no longer able to swallow safely the medications that have kept him or her comfortable.

The continuous infusion obviates the need for repeated injections and so prevents recurrent pain that can occur if the medications are given intermittently. Death in these circumstances is anticipated. It is not the result of the infusion.

c) Consider what type of legislative change may be required

Currently, only four countries have legalised euthanasia, the Netherlands, Belgium, Luxembourg and Colombia.
PAS is legal but *Euthanasia is illegal* in Switzerland, Japan, Germany, Canada and the US states of Washington DC, Washington, Oregon, Colorado, Vermont and Montana.

The WAPMSG do not believe that there is a need for change in the current legislation.

The WAPMSG do not support legalised Euthanasia or PAS.

If there are to be changes to the current legislation, the WAPMSG advises caution as follows:

i. Euthanasia and PAS must be restricted to the end stage of life limiting illnesses when all other options have been explored. This will need to be confirmed by two independent specialists in the relevant illness, e.g. oncologists or palliative care consultants in the case of cancer, 2 cardiologists in the case of end stage heart disease.

ii. There needs to be adequate engagement with a Palliative Care Team before suffering is deemed intolerable.

iii. The request must be in writing, the patient must be certified of sound mind, the request must be voluntary and repeated after a cooling down period of four weeks.

iv. A Substitute Decision Maker should not be able to request Euthanasia or PAS on behalf of the patient, even if he or she is the appointed Guardian.

v. Euthanasia and PAS should be limited to long term residents of WA to avoid suicide tourism as happens in Switzerland.

vi. Each individual doctor must have an *unalienable* right to refuse to participate in Euthanasia and PAS. It must be expressed concretely in the Law that it would be illegal to bring pressure to bear on any doctor who chooses not to participate in Euthanasia and PAS. Organisations must also have an *unalienable* right to refuse to participate in Euthanasia and PAS and should not in any way be discriminated against or coerced.

WAPMSG is concerned that in the Netherlands and Belgium cases of involuntary Euthanasia have been reported. Strong safeguards are needed to protect incompetent patients.

If the current legislation is to change, it is imperative that the vulnerable are protected. The elderly with dementia, persons with disabilities, young children and the elderly in general who are physically frail should not be made to feel a burden on family and society and resources should be available to support their care.

d) Examine the role of Advance Health Directives, Enduring Power of Attorney and Enduring Power of Guardianship Laws

Advanced Health Directives can be very useful to allow a person to clearly state their preferences for their end of life care. The community needs ongoing education to utilize this mechanism to ensure their care preferences are recorded and incorporated into their future medical care.

The Enduring Power of Guardianship gives the Guardian the authority to make medical decisions on behalf of the person who gave the EPG. As such the Guardian has a very important role in determining what medical treatments should be considered at their end of life. If euthanasia is legalized then the role of the guardian needs to be re-examined as to their capacity to make decisions for the patient in this regard.

Conclusion:

Death is the closing chapter of the story of a person's life journey.

Dignity is inherent to every person and needs to be nurtured and respected by the community. To maintain a person's dignity as health professionals we are called to acknowledge and alleviate their suffering. We need to respond to any physical suffering with evidenced based strategies. We need to respond to any social, emotional suffering with the appropriate support. No person should need to contemplate ending their own life because of a lack of a response from a caring community. As studies indicate the primary motive for euthanasia is not uncontrolled pain. It is more commonly requested when a person loses their meaning in life or that they feel that they are a burden to others. The provision of readily accessible, high quality palliative care is a fundamental need that must be guaranteed in any deliberation of our end of life care. Euthanasia is not an antidote for suffering and indeed may cause more unintended suffering.

Utmost care must be taken to protect the vulnerable and voiceless members of our society.It must ensure that no one, professional or other, and no organisation is forced/coerced into participating in Euthanasia/PAS against their conscience

Additional questions for the committee to consider

How will the practice of euthanasia/PAS be controlled and monitored?

What mechanisms will be used to keep medical practitioners who practice euthanasia /PAS accountable to the community?

What credentialing will be required to ensure that practitioners authorizing the practice fit the requirements of the legislation?

Will prescribing practitioners be obligated to write the death certificate?

What cause of death will be required to be recorded?

We write as independent medical practitioners, not on behalf of any organisation or employer. We would be willing and keen to be involved in any future discussions on end of life care.

On behalf of the members of the WAPMSG

Dr Kevin Yuen
Chair of the WAPMSG