



## **JOINT SELECT COMMITTEE ON END OF LIFE**

### **CHOICES PROPOSED QUESTIONS**

#### **PALLIATIVE CARE WA**

##### **Purpose of this hearing**

The purpose of this hearing session with Palliative Care WA is to gain an understanding of the existing systems, policies and laws in Western Australia relating to end of life choices. In doing so, Committee members should consider if the existing systems, policies and laws:

- Adequately support and protect individuals and their families from unnecessary stress or pain at the end of life.
- Are clear, transparent and well understood, or is there confusion regarding their operation?
- Sufficiently respond to the needs and expectations of the community.

##### **Witness**

**Dr Elissa Campbell, President, PCWA**

**Ms Lana Glogowski, Executive Officer, PCWA**

**Ms Cait Calcutt, Carer & Projects Officer, PCWA**

**Ms Natalie Panizza, Palliative Care Nurse Practitioner, Royal Perth Hospital**

##### **Introductory Comments**

Palliative Care WA is the peak body for palliative care in Western Australia (WA). Its members include individuals and organisations who support our mission of awareness of and access to quality palliative care for all Western Australians.

We firmly believe that Palliative care should be available to anyone with life-limiting disease whose quality of life is being impacted by their illness. Palliative care focuses on the holistic needs of patients through careful management of pain and other symptoms, and the provision of physical, psychological, social and spiritual care. Importantly, palliative care recognises the needs of caregivers as well as patients.

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Palliative care is broadly divided into specialist palliative care and non-specialist palliative care.

**Specialist palliative care** is services provided by health professional teams who have recognised qualifications or training in palliative care & who provides direct care to patients with complex palliative care needs, or provides consultation services to support, advise and educate other health care teams who are providing end-of-life care.

**Non-specialist palliative care** may be provided by a person's primary care team (eg GP) or other doctors such as Geriatricians or Oncologists, and other health care professionals such as nurses, OTs or social workers.

Before responding to the questions we would like to say that sixty minutes is inadequate to address the breadth of questions, about very complex issues, in the depth that they deserve.

## 1.0 Advance Care Planning

- **Definition**

ACP is a process by which people can express their values and wishes regarding future medical treatment should they no longer have the capacity to communicate those wishes. This includes discussions with loved ones and/or health professionals, and may also include preparing a written AHD or appointing EPG. It is not limited to documents alone with conversations being a critical first step. ACP is a valuable tool to facilitate end-of-life choices that is unfortunately very under-utilised in WA and poorly understood by the community and health care providers.

- **Strategic Priority**

PCWA has been engaging and informing the community on ACP as a strategic priority and highly advocates for increasing the level of resources allocated to providing training in palliative care and end-of-life planning at both health professional and community levels

- **PCWA service delivery**

PCWA has been highly successful in both engaging and delivering ACP workshops in Perth metro and some regional centres (2017 Evaluation report submitted as evidence)

- **Public health approach**

PCWA believes that this is a significant public health issue that needs to be delivered in partnership with primary health providers

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## 2.0 Palliative Care in Western Australia

- **Low levels of understanding**

Palliative care as a discipline is poorly understood by both the community and health providers with little information publicly available, health providers not actively referring, a reticence to discuss the issue, misconception that palliative care is just for the final days or weeks of life, or just for people with cancer. In fact it is for anyone with a life-limiting illness, who may have months or even years to live, and can be provided in combination with life-prolonging therapies like dialysis or surgery.

- **Poor access**

Palliative Care Outcomes Collaborative or PCOC, a national program that collects data from specialist palliative care services, has shown specialist palliative care to be highly effective. However, access to good quality palliative care across WA is highly variable and PCOC estimate that currently 60% of WA residents who would benefit from access to palliative care are missing out. Additionally, current palliative care services have insufficient capacity to meet growing demand.

In addition, referral to specialist palliative care services often occur in the last few days or weeks of a person's life, despite international and local evidence showing that there is greater benefit from referral earlier in the disease process, such as at the time of diagnosis with life-limiting illness. Early referral has been shown to improve the person's quality of life, reduces the number of medical interventions and hospitalisations, without hastening death.

- **Innovation**

PCWA suggests that there is a need to explore a range of new and innovative models of care (to reduce the medicalised focus and meet existing gaps in services). Cultural change is required in society's approach to death and dying as a failure of medicine. Novel approaches include the Compassionate Communities approach, which links existing Community networks to support a person with palliative care needs.

- **Obstacles to patient choice**

Most Australians say that they would prefer to die at home and certainly most people wish to live at home for as long as possible even if the last days or weeks are spent elsewhere. Obstacles to patients being cared for and dying in their place of choice include people not making their wishes known early via ACP, even if ACP in place then not being followed through by health professionals (due to lack of registry for AHDs, or health professional not understanding ACP), referral to palliative care occurring too late in the person's life, families' lack of resources or capacity to support the patient's wishes, lack of family networks, lack of community-based clinical supports eg aged care package;. For those who wish to die in hospices, there are limited beds available in WA & these are not equitably distributed across the metropolitan area or in the rest of the state.

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- **Poor access for non-malignant illnesses**

- An Australian study published this year, which included WA participants, interviewed the bereaved caregivers of people who received palliative care. This study indicated that 64% of people with cancer had received palliative care in comparison to on 4-10% of people with other non-cancer illnesses. We would like to present slides summarising this study, from the first author Prof Samar Auon, as evidence to the committee.

- **Prescribing protocols for drugs in palliative care**

Federal & State laws are in place regarding the prescription of S8 (opioid) and all prescription medications. WACPCN has produced Evidence based clinical guidelines for adults in the terminal phase which guides prescribing these medications for the dying person. Also, palliative care specialist doctors have at a minimum 7 years' experience as doctors and undergo at least 3 years of specialist training in palliative care, during which they become experts in prescribing such medications.

### 3.0 Limitations of Palliative Care

- **No guarantee**

It is important to recognise that no medical treatment can guarantee a 100% outcome and palliative care is no different to other disciplines. Palliative Care Outcomes Collaboration (PCOC) data shows that specialist palliative care services in Australia are highly effective (see Dr Kathy Eagar's The Conversation article "No, most people aren't in severe pain when they die"). Prof Eagar is available to be contacted by the Committee if they require further detailed information

- **Common symptoms of the dying person**

Fatigue is the most common symptom – in 2016 13.3% of patients reported feeling severe distress due to fatigue at the start of their palliative care. This was followed by pain (7.4%) and appetite (7.1%) problems. Distress from fatigue and appetite is not surprising as a loss of energy and appetite is common as death approaches while most pain can be effectively managed. Other problems such as breathing, bowels, insomnia and nausea are experienced less often and these typically improve as death approaches.

Contrary to popular perceptions, people in their final days and hours experience less pain and other problems than earlier in their illness trajectory. In 2016, about a quarter of all palliative care patients (26.0%) reported having one or more severe symptoms when they commenced palliative care and this percentage decreased to 13.9% as death approached. Pain is much less common

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than fatigue. In total, 7.4% of patients reported severe pain at the beginning of their palliative care and only 2.5% reported severe pain in the last few days. Breathing difficulties cause more distress than pain in the final days of life.

- **Individual choices**

These figures must be considered in relation to a person's wishes. There are a small number of patients whose pain and other symptoms are not adequately relieved by existing medications and other interventions. But some patients who report problematic pain and symptoms elect to have little or no pain relief. This might be because of personal or religious reasons. Some patients, for example, elect little or no pain relief because they do not want to feel drowsy, a common side effect of pain medication. Patients and family make end of life decisions that need to be respected by the clinical team

- PCOC benchmarks

It is important to note that PCOC benchmarks are identical for both hospital inpatient and community palliative care.

#### 4.0 End-of-Life care – Refusal of Medical Treatment

- **Informed Patient Choice**

Palliative care respects informed patient choice including the refusal of any or all medical treatments; this is achieved by emphasising communication with the patient (particularly listening rather than talking) and providing the best quality holistic care

- ***Palliative Care Principles***

With regards to the questions regarding practices described as “Refusal of Medical Treatment”, “Palliated Starvation & Dehydration”, “Terminal Sedation” and “Doctrine of Double Effect”, it is important to understand a number of palliative care principles:

- ❖ Palliative care respects informed patient choice with an emphasis on communication to understand the patient's wishes and values regarding medical treatment, in order to support them with decision making. This requires them to be informed about the potential benefits and side effects of any treatment. Ideally, the loved ones are also aware of these discussions. If the patient lacks capacity to make decisions regarding medical treatment, and no AHD is in place, then the person authorized by WA law would be involved in informed decision making.
- ❖ Consent, either implicit or explicit, is obtained before making any treatment changes, such as changing the route of administration of medications (eg from tablet to injection), not only those practices specifically mentioned in the questions. In addition, treatment recommendations are generally made by a multidisciplinary team (eg nurses, allied health), rather than an individual doctor.

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- ❖ This focus on constant communication and multidisciplinary decision making are absent from many other parts of the health care system.
  - ❖ The focus on communication, and respecting the patient's values and wishes, assists in maintaining trust between health professionals and patients. For this reason, in our experience, the relationship between specialist palliative care professionals and patients is far less likely to be compromised than in general across the health care system. It also reduces the likelihood of substitute decision-makers for vulnerable people exploiting their position in their own interests?
  - ❖ We would say that all the practices described below are well-understood by the specialist palliative care workforce but not the general health care workforce or community.

- **Rational patient decision-making**

"Refusal of medical treatment" is a broad term describing a competent person not giving consent for a particular medical treatment that is offered. This term may be seen as pejorative, implying that a patient is being difficult or irrational. However, usually such a decision is made by a rational person with a life-limiting illness, who is informed of the potential risks and benefits of a treatment and weighs these up against their value and wishes.

**Examples:**

- ❖ A patient may decide not to have haemodialysis to treat their chronic kidney disease, as they do not think that the potential benefit (living a few extra months) is worth attending hospital 3 days a week and experiencing side effects.
- ❖ A nursing home resident, who has had multiple recent hospitalisations with pneumonia, may elect to stay in the nursing home with the next bout of pneumonia, and receiving symptom control, accepting that this is likely to result in death.
- ❖ A person, who is receiving tube-feeding because it is unsafe for them to swallow, may elect to eat and drink as they feel the quality of life gained outweighs the risk of choking or pneumonia.

- **Suicide**

Good palliative care includes assessment of a person's mood and mental state. If suicidality were identified or suspected, referral to a psychiatrist would take place. This is just one reason that it is important that people with palliative care needs have good, timely access to mental health services.

- **Who administers medication?**

Under WA law, only nurses and doctors are permitted to administer medications in hospitals or hospices. At home the patient and their carer can administer medications as well as doctors and nurses.

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## End-of-Life care – Palliated Starvation and Dehydration

- **Eating and drinking as required**

People who are very unwell often lose their appetite. This is a natural part of the dying process. In addition, people who are dying are often restricted in their physical activity or even bed bound and so their bodies do not require the same amount of food and fluids they once did. They do not “starve to death” or die of thirst. Artificial nutrition and hydration can lead to unpleasant side effects like choking or swelling, without prolonging life. In general in specialist palliative care, the dying person can “eat and drink as desired”. Usually this is only a few spoonfuls of their favourite ice cream or whiskey. “Mouth care”, which is keeping the mouth moist with swabs, ice chips, etc, is also very important for the comfort of the dying person & part of the WA Health “Care Plan of the Dying”

- **Refusing food and fluids?**

In our experience, it is extremely rare in WA for people attempting to hasten death by stopping eating and drinking. People who are receiving artificial nutrition, eg via a feeding tube, or hydration, via a drip, may elect to stop these.

## End-of-Life care – Terminal Sedation

- **Purpose of terminal sedation**

Terminal sedation is sedation designed to relieve extreme distress in a person who is imminently dying, usually the last hours or days of life. Sedation should be appropriately used for the control of specific symptoms once all other alternatives have been considered and found to be ineffective or inapplicable. The most common refractory symptoms requiring sedation are reported as delirium, which is acute confusion often characterized by agitation, (54%) and breathlessness (30%) (data from a systematic review by Maltoni & colleagues).

The same review found no evidence that terminal sedation led to hastened death.

- The palliative care approach advocates managing the dying person’s symptoms in the terminal phase in order to relieve suffering and maintain dignity.
- It is also important to recognise that for many people the level of pain in the terminal phase is less than earlier stages of the illness journey

## End-of-Life care – Doctrine of Double-effect

- **Definition**

White, Wilmott and Ashby define “the doctrine of double effect is that an act performed with good intent can still be moral despite negative side effects. In the context of palliative care, this can arise when four conditions are met:

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1. Administering palliative medication is not, in itself, immoral;
  2. The intention is to relieve pain, not to hasten the patient's death;
  3. The relief of pain is not achieved through causing the patient's death; and
  4. Proportionally, the need to relieve pain is such that it warrants accepting the risk of hastening death.

- **Evidence in practice?**

However, 2005 study by Phillip Good et al, of people who died in an Australian hospice, found no evidence for the doctrine of double effect – there was no association between the doses of opioids and sedatives on the last day of life and survival (from hospice admission to death).

Quality palliative care should not need to use the principle of double-effect as a justification for the administration of opioids and sedative.

- It is also important to note that leaving symptoms such as pain untreated may also hasten death.
- Such medications are rarely administered increasingly in specialist palliative care in WA. The most common refractory symptom requiring sedation is reported as delirium (54%) (Maltoni et al). In WA (like all of Australia) we use an antipsychotic medication – haloperidol (non-sedating at low doses used) to relieve delirium and therefore the doses of sedative we need in these circumstances are usually lower than those reported in other countries.
- Good palliative care includes the relieving of distressing symptoms (unless the person requested otherwise). If first line therapies are not effective then it may be necessary to use second line therapies (some of which are sedating) to relieve those symptoms.

### **End-of-Life care – Legal Issues and end-of-life choices**

- **Awareness of legal requirements**

In our view, specialist palliative care workers, particularly doctors, are aware of the existing legal requirements associated with end of life choices. This is less so for other health professionals. This is supported by a study of Australian doctors by White et al who found that specialists in geriatric and palliative medicine had significantly higher knowledge than specialists in five other specialties (emergency medicine, intensive care, medical oncology, renal medicine and respiratory medicine), of laws on withholding and withdrawing life-sustaining treatment. (NB did not include WA)

- **Education opportunities**

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There has been limited education available for health professionals since the enactment of legislation in WA in 2010 re ACP & EPGs. Research I conducted at 3 Perth hospitals showed that 61.9% of health professionals who responded were not aware of the WA health online learning module about ACP, and only 22 (6.0%) respondents reported completing this.

- **Accessing Legal Advice**

Palliative Care WA is not a source of legal advice. Practitioners would usually contact their medical indemnity organisation or hospital legal department in the rare event of a legal dilemma.

- **Call for public education campaign**

We call for a public education campaign, similar to the Organ Donation campaign, to improve knowledge around palliative care, ACP & making choices at the end of life. A parallel campaign to improve awareness, knowledge and expertise of health professionals is also required.

**Conclusions:**

1. **Quality Palliative care is highly effective**
2. **Specialist palliative care services are doing a great job. We have some world-leading services e.g. Silver Chain Hospice**
3. **Unfortunately, ~60% of people who could benefit are missing out, due to a number of barriers (systemic, cultural and medical) and inequities (based on geography, demography, diagnosis and socio-economic factors)**
4. **PCWA can assist the committee in suggesting novel models to improve access to palliative care**
5. **For less novel but equally important suggestions, see Recommendations 1-48 of the Victorian Enquiry into End of Life Choices**
6. **60 minutes is inadequate to discuss these important issues**

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***Natalie Panizza – Nurse Practitioner, Royal Perth Hospital***  
***Cait Calcutt – Projects Officer PCWA and carer***

