

## Palliative Care WA's Response to Questions on Notice from Joint Select Committee on End of Life Choices 19/12/2017

### Introduction

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 symptoms. Palliative care focuses on the holistic needs of patients through careful assessment, 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.

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 accredited training in palliative care & who provides direct care to patients with complex palliative care needs, and/or provides consultation services to support, advise and educate specialist and non-specialist teams who are providing end-of-life care.

*Non-specialist palliative care* may be provided by a person's primary care team (GP and other primary care team providers) or other doctors such as Geriatricians, General Physicians or Oncologists, plus other health care professionals.

### Regarding Questions taken on notice

The Committee requests that Palliative Care Inc. provide a response to the following questions provided to it before the hearing but not answered due to time constraints.

1. In what ways do you think palliative care could be better integrated across the WA health services?

Integration is a major issue both between services and between sectors such as social and community care services.

Many people the need for 'joined-up' or integrated services and were concerned that patients' quality of life and death may be compromised by the lack of coordination between health and social care providers.<sup>1</sup> Patients approaching end of life with multiple chronic diseases need often services from several health care providers. Multi-morbidity poses a significant and growing challenge to the provision of integrated healthcare within the often fragmented health and social care systems of high income countries, including Australia.<sup>2</sup>

1. Nelson A. Beyond the questions: Shared experiences of palliative and end

of life care. Cardiff: Marie Curie Palliative Care Research Centre; 2016.

2. Hujala A, Taskinen H, Rissanen S. Policy Brief 26: How to support integration to promote care for people with multimorbidity in Europe? Utrecht: Nivel and Technische Universitat Berlin; 2016.

2. In your view is the WA health system responsive to consumer demand for palliative care?

In some areas but there remain many people who are not able to access pc who would benefit from such access. People living in region, rural and remote WA, people from lower-socio economic backgrounds (e.g homeless as most palliative care services are delivered in the home or in residential aged care facilities) and those who do not have a cancer diagnosis.

Despite a growth in palliative care services, access and referral patterns are inconsistent, even in high income countries, and only a minority of people who would benefit from such care receive it (Love & Liversage, 2014).

3. What are the challenges facing the palliative care work force and volunteers in the provision of palliative care?

Whilst the provision of general palliative care is crucial and suits many people and situations, there are insufficient palliative care specialists.

There are issues with worker burnout as too few resources, lack of referral pathways, too few supports for family and unpaid caregivers in the home (e.g. HACC services generally only provide around 14 hours care per week) which results in return to hospital as caregivers unable to cope.

Practitioners providing end of life care report a sense of satisfaction alongside feelings of gratitude and an increased sense of spirituality<sup>1</sup>. However, providing care at the end of life has challenges. Health professionals face suffering on a daily basis and routinely encounter intractable illness, patient death, and family members' grief<sup>1</sup>. Long hours and increasing patient numbers exacerbate negative experiences. A survey of German palliative care physicians (n=873) found that 51% reported feeling burdened when they could not achieve the objectives of palliative care; 47.2% identified burden related to building relationships with patients and families; and 42.6% felt that confronting patients' deaths was burdensome<sup>2</sup>. A Canadian study of 42 nurses providing end-of-life care reported that difficulties managing emotions and ongoing exposure to suffering caused intense distress<sup>3</sup>.

1. Graham, J., Ramirez, A. J., Cull, A., Finlay, I., Hoy, A., & Richards, M. A. (1996). Job stress and satisfaction among palliative physicians. *Palliative Medicine*, 10(3), 185-194.

2. Müller, M. et al. (2009). Wie viel Tod verträgt das Team?. *Der Schmerz*, 23(6), 600.

3. Sinclair, S. et al. (2016). Compassion in health care: An empirical model. *Journal of pain and symptom management*, 51(2), 193-203.

4. What proportion of palliative care to the community is provided by volunteers, charitable groups and other non-government agencies?
5. Are there protocols for prescribing opiate, or derivative, or any other sedating, or pain relieving, medications for the purpose of palliative care?

- **Low levels of understanding**

Palliative care as a discipline is poorly understood by the community and health providers with little information publicly available, health providers not actively referring, and 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

- **Poor access**

Currently access to good quality across WA is highly variable with PCOC data indicating that currently 60% of WA residents who would benefit from access to palliative care are unable to do so. Additionally, current palliative care services have insufficient capacity to meet growing demand.

- **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 perhaps with a new mindset e.g. the Compassionate Communities approach

- **Obstacles to patient choice**

Obstacles to patients being cared for and dying in their place of choice include people not making their wishes known early i.e. ACP, families lack of resource or capacity to support the patient's wishes, lack of family network, lack of community-based clinical supports eg aged care package; 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)

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

Research indicates that more people with cancer (64%) had received palliative care in comparison to other non-malignant illnesses (4-10%) with these non-malignant diseases are still under-represented in palliative care ten years on from an earlier study where it was reported that less than 10% of people who died of non-malignant diseases had accessed specialist palliative care services, compared with 66% of people who died of cancer.

- **Opiate protocols**

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.

6. Many submissions expressed deep admiration and gratitude for health professionals and carers in the area of palliative care - does this work extract a cost from individuals, in comparison to other areas of health care and volunteering?

a. Are there additional supports for palliative care workers and volunteers?

b. In your experience what is the rate of turnover of staff, contract workers and volunteers in palliative care?

Research suggested that there is burnout, compassion fatigue and stress that may compromise patient care.

7. Can you recommend any sites in the metropolitan area or regions that would be appropriate and beneficial for the Committee to visit?

St John of God Murdoch Community Hospice

Great Southern (Albany)

8. Can you explain why the national PCOC (Palliative Care Outcomes Collaboration) benchmark for community palliative care providers is 60% relief of pain and suffering compared to the 90% benchmark for those in hospital?

PCOC benchmarks are identical for both hospital inpatient and community palliative care

9. Are the current laws too constraining on health professionals providing palliative care?

a. What do you think could be improved?

10. Would you say the arrangements relating to refusal of medical treatment are well understood and respected by the palliative care workforce and volunteers consistently in WA?

a. On what basis is this distinguished from conduct which might otherwise be a suicide attempt?

b. In your view does permitting the refusal of medical treatment compromise efforts to reduce suicide generally in the community?

c. Based on the feedback you receive from the palliative care workforce, including volunteers, is the relationship between health professionals and patients compromised by permitting the refusal of medical treatment?

d. Are you aware whether or not the palliative care workforce has any concerns that vulnerable people are being influenced or coerced into refusing medical treatment?

e. Are there any concerns that substitute decision-makers for vulnerable people are being influenced to refuse medical treatment or are exploiting their position in their own interests?

11. Do palliative care workers report incidents where medical treatment is refused?

## 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.
- ❖ 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.

12. The refusal of medical treatment can include refusing artificial hydration and nourishment, as in the Rossiter case.
  - a. In your view is this issue now clear for palliative care workers?
  - b. Do you consider that the practice is implemented consistently across WA?
13. In your experience do palliative care workers and volunteers easily distinguish a patient's refusal of nourishment and hydration from conduct that might otherwise be a suicide attempt?
  - a. Can patients be treated with pain relieving or sedating medications until they die?
  - b. In what circumstances can a GP provide pain relief to a patient who is refusing nourishment and/or hydration?
14. In your opinion is the bond of trust between health professionals and a patient compromised by permitting palliated starvation?
15. Are you aware of any concerns that vulnerable people are being influenced or coerced into agreeing to palliated starvation?
16. Are you aware of any concerns that substitute decision-makers for vulnerable people are being influenced to agree to palliated starvation or are exploiting their position in their own interests?

#### 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

17. Are you aware of any concerns that vulnerable people are being influenced or coerced into agreeing terminal sedation?

18. Are you aware of any concerns that substitute decision-makers for vulnerable people are being influenced to agree to terminal sedation or are exploiting their position in their own interests?

19. What is the doctrine of double-effect?

20. Generally, what medications are involved in cases where this doctrine may apply?

21. In your experience under what circumstances are such medications increasingly administered?

22. Is this recognised as good palliative care practice?

a. Is the consent of the patient required? (Or the consent of their authorised person for medical treatment decisions).

b. Are there circumstances in which a palliative care worker can decide to administer such medications on the patient's behalf?

23. In your experience does increasing the amounts of such medication(s) - with the attendant risk - compromise the relationship between health professionals and their patients?

24. Are you aware of any concerns that vulnerable people are being influenced or coerced into consenting to dangerous levels of pain relief?

25. Are you aware of any concerns that substitute decision-makers for vulnerable people are being influenced to consent to dangerous level of pain relief or are exploiting their position in their own interests?

#### 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:

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.

26. Do palliative workers and volunteers seek assistance from Palliative Care WA on the legal implications of end of life decisions made by either the person they care for, or if they are authorised to do so on their behalf?

27. Is it your experience that the existing legal complexities in this area cause additional stress or dilemmas for palliative care workers or volunteers whilst caring for people who are at the end of their life?

a. If yes, what do you think might assist carers to deal with the legalities associated with

## 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**

There has been limited education available for health professionals since the enactment of legislation in WA in 2010 re ACP & EPGs. Research conducted by Dr Elissa Campbell (unpublished) 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. The issues raised by the committee are important and complex and Palliative Care WA would welcome further opportunities to discuss these with committee.



# COMMUNIQUÉ

## CEO SECTOR ROUNDTABLE ON PALLIATIVE CARE

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*The CEO Roundtable on Palliative Care provides high level advice to the Minister for Health, Hon. Roger Cook, MLA on palliative care issues in WA. The Roundtable is facilitated by Palliative Care WA with CEO's drawn from PCWA member organisations in the health and community service sectors.*

This first communiqué from the CEO Roundtable on Palliative Care reports on two meetings; an introductory meeting held on 12<sup>th</sup> October focused on identifying key issues and the second with the Minister for Health on 26<sup>th</sup> October.

Current members of the CEO Roundtable on Palliative Care include:

- Dr Scott Blackwell (Collaborative Primary Health Care)
- Pip Brennan (Health Consumers Council)
- Paul Coates (Carers WA)
- Stephanie Dowden (PCWA)
- Jennifer Lawrence (Brightwater)
- Chris McGowan (Silver Chain)
- Yasmin Naglazas (Bethesda Health Care)
- Rhonda Parker (Alzheimer's Association)
- Alison Parr (St. John of God Hospitals)
- Ashley Reid (Cancer Council WA)
- John Van Der Wielen (HBF)

Amanda Bolleter (WACPCN) participated as an observer.

Below is a summary of the main issues discussed.

### LOW AWARENESS OF ADVANCE CARE PLANNING & PALLIATIVE CARE

Research has clearly identified that many people wish to die at home (or in their aged-care facility) rather than hospital but few know how to plan for this to happen. This is often compounded by health providers who are uncomfortable, or view it as a failure, to have a conversation with their patients about planning the last stage of life.

Advance Care Planning (ACP) provides mechanisms for people to make plans that reflect their personal values and priorities and appoint substitute decision makers for when capacity may be lost. PCWA has been offering workshops to provide information on both ACP and palliative care approaches to keen audiences across the state but is observing very low levels of participant knowledge at the outset.

### IMPORTANT ROLE OF CARERS

The implication of people wanting to die at home is the burden of care that falls to family members. Most families are unprepared for this task and the value of establishing a supportive community around them is critical e.g. the Compassionate Communities approach. Similarly the opportunity to access respite services is critical to reducing inappropriate and expensive

hospital admissions. Current access to respite is limited and consideration needs to be given to funding this service separate to care packages. The provision of “night sits” was identified as a cost-effective support for families.

### **WHO PAYS?**

CEO members recognised that further work was required to ensure that both public and private sectors were meeting the costs associated with providing quality palliative care. There seems to be a significant opportunity to further develop a range of care models in community and aged-care settings e.g. encouraging GPs to deliver clinical support with specialist consultancy back-up.

### **DIFFICULTY NAVIGATING THE SYSTEM**

Anecdotal feedback shared by many CEOs indicated that the health and aged-care system had become complex to the point that most people found it very challenging to navigate. A number of agencies were providing informal information and support to their members but the lack of a formalised system raised important questions regarding universal equity and access.

### **USING ANALYTICS TO INFORM SERVICES**

Currently 14,000 people die per year in WA and of those 7000 were expected deaths. The WA Cancer and Palliative Care Network of the WA Health Department are closer to being able to gather and analyse public, and some private sector, activity data in a standardised and streamlined format. It was also recognised that most agency members of the CEO Roundtable were collecting significant internal data that collectively could provide insight into the journeys and experiences of people dying in our communities. It is important to use this data to inform best practice moving forward.

### **SUPPORTING VULNERABLE POPULATIONS**

Birth and death are universal experiences, and while cultural and spiritual differences need to be

recognised, most people aspire to a death that is free from pain and symptoms, at a place of their choosing surrounded by those they love. However, the complexity of the current system and lack of knowledge re: palliative care and Advance Care Planning results in vulnerable populations being significantly disadvantaged. Emerging evidence suggests that ATSI, CaLD, people with disabilities and mental health issues, LGBTIQ and rural & remote communities are less likely to experience a “good” death.

### **BUILDING COMMUNITY CAPACITY**

Since the 1950’s, health systems in the developed world have focused their capacity on curative processes and to extend life. Unfortunately, for many health professionals the delivery of palliative care is almost code for “giving up”. There is a need to re-orientate community discussion away from ageism and a sense of burden to one of valuing older community members and supporting family resilience in caring for them. Outcomes might include more people dying at a place of their choosing in a way that reflects their priorities and values. This may also include fewer stays in hospital with less unnecessary and unwanted treatments.

### **RAISING ISSUES WITH THE CEO ROUNDTABLE**

*The CEO Roundtable of Palliative Care is keen to represent the views of the health and community services sectors. Should you have an issue that you would like to raise, please make contact with PCWA’s Executive Officer, Lana Glogowski on [pcwainc@palliativecarewa.asn.au](mailto:pcwainc@palliativecarewa.asn.au)*

#### **Next meetings of the CEO Roundtable:**

- Thursday 1<sup>st</sup> February, 2018 (preparation)
- Thursday 8<sup>th</sup> February, 2018 (with Minister Cook)

*Prepared 11 December, 2017*