

# 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) or 0419 047 315.*

#### **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*