

CEO Roundtable for Palliative Care

Communiqué 9

Meeting on Wednesday 17 April 2024

At our April *CEO Roundtable for Palliative Care in WA* meeting, 16 representatives from organisations with an interest in palliative care, met to unpack WA's capacity to deliver Palliative Care Australia's Budget Ask that had three main themes:

1. Palliative care at home for people under 65 who have functional support needs circa \$7.8m annually for WA, noting the national request was for \$77.6m over three financial years to support approximately 3,000 people.
2. Continuation of Comprehensive Palliative Care in Aged Care (CPCiAC) circa \$3.8m annually for WA. Nationally this is \$33m matched by states and territories over three financial years.
3. Funding for review of how to improve access to after-hours palliative care services by analysing gaps in service provision – \$300,000 as a special project.

In addition, the participants were asked to consider what the "ask" from the sector would be for the forthcoming State election.

Continuation of Comprehensive Palliative Care in Aged Care (CPCiAC)

CPCiAC is a joint Australian Government and State/Territory-funded initiative. Comprehensive consultation identified nine projects in WA, with all funding ceasing on 30 June 2024. WA's programs that were selected as part of the funding are listed below:

Project	Scope	Description
1. Metropolitan Palliative Care Consultancy Service (MPaCCS) expansion Bethesda Health Care	Metropolitan	Expansion of the specialist in-reach model to build RACF staff capability using patient-based care episode and scenario training. The expanded model aims to increase RACF residents' access to quality specialist EOL&PC in the outer east metropolitan region and support the metropolitan-wide coordination of integrated EOL&PC across hospitals and RACFs. Trialing extended services for: extended weekday services of the social work stream; expand the hospital liaison nurse service across Perth metropolitan area; an on-call phone nursing service to 7.30pm on weekdays.
2. Residential Aged Care Excellence in Palliative Care (RACEPC) Communicate Cancer Council WA	Statewide	Provides online targeted education to RACF staff with a focus on communication and recognising and responding to the deteriorating resident. It aims to develop RACF workforce capability to provide quality EOL&PC to residents, families and carers. The online program includes virtual methods of education delivery (for clinical and non-clinical staff) integrated webinars, and AI technologies to enhance user experience.

3. Transition Support Navigator pilot NMHS - SCGH	Metropolitan	Establish a pilot role to proactively facilitate integration of care at points of transition for inpatients +65 years referred to Transition Care RACF at time of discharge from hospital. The role is hospital-based and provides specialist support within the acute hospital setting at key points of transition and supports transitional care providers and/or RACFs.
4. Care Coordinator pilot SMHS - RGH & FH	Metropolitan	Develop and implement two pilots in two separate hospitals: <ol style="list-style-type: none"> 1) Rockingham General Hospital – target patients admitted to hospital from a RACF and discharged to a RACF/Transitional Care Facility for the first time to support transition. The role works across all wards (priority given to general medical and aged care/rehabilitation wards) and liaises frequently with the geriatric and palliative care teams. 2) Fremantle Hospital – support ACP for patients within the hospital’s Comprehensive Care Centre entering a RACF/Transitional Care Facility for the first time.
5. Transition Support Officer pilot EMHS - RPH	Metropolitan	Develop and implement a pilot to: <ol style="list-style-type: none"> 1) work with RACFs in the catchment with high volumes of hospital presentations and undertake audits to guide time-limited quality improvement support for ACP documentation, and support access to this information during transition between the RACF and hospital. 2) support ACP for hospital inpatients transitioning to RACFs/Transitional Care Facilities for the first time, including transition of information at discharge.
6. GP Case-conferencing Coordinator pilot WAPHA	Metropolitan	Pilot project for four dedicated case-conferencing coordinators located in metropolitan RACFs whose role it is to support primary care coordination between GPs and RACFs, coordinate case conferencing aided by Medicare Benefits Schedule items, and develop systems and processes to be sustainable for GPs and RACFs. The aim of the role is to provide an additional resource to support RACFs and decrease the administrative burden on GPs.
7. Residential Care Line (RCL) expansion	Metropolitan	Provide acute clinical support to RACFs including palliative-related care, symptom management, and identifying need for ACP and Goals of Care discussions. Deliver the <i>Clinical Deterioration</i> education package to upskill RACF clinical staff on recognising and responding to the deteriorating resident. Complex palliative care referrals are made to other services as required.
8. GP information resources RACGP	Statewide	Develop a toolkit/business model to support GPs to access and deliver services in RACFs, in addition to mentoring from existing RACF GPs. The aim is to support GPs with information and resources to enhance their business and care provision in an RACF setting.
9. Residential Goals of Care (RGoC) WACHS	Country WA	Adapt the Goals of Care document and process currently used in hospital settings to RACFs and pilot the form and process in WACHS RACFs. The tool supports clinical care, provides common language across settings, and complements ACP. It promotes conversations about goals of care, limits of escalation of care, whether the resident wants to go to hospital, and may trigger ACP. Expansion of the pilot to metropolitan RACFs is a by-product and currently underway.

A review is being currently undertaken to determine the effectiveness of these programs. Given the timing, Palliative Care Australia and all the state-based organisations have supported the continuation of investment into funding improvements in palliative care.

Additional services for palliative care at home for people under 65 who have functional support needs

At the heart of the PCA Federal Budget submission are proposals to increase access to functional day-to-day living supports for people wanting palliative care at home, including people with disabilities. This community-based approach allows people to live well and remain at home for as long as possible.

People with life-limiting illnesses who receive palliative care at home have fewer hospital admissions, shorter stays in hospital when admitted, spend less time in emergency departments and intensive care units, and use ambulance services less frequently. People receiving care at home:

- visit an emergency department between 2% and 12% less in their last year of life (when compared with people with life-limiting illness who don't receive care at home)
- have reduced days in hospital during their last year of life, of between 4.5 and 7.5 days.
- are twice as likely to die at home, where 70 per cent of Australians say they wish to die.

It is clear the situation for people under 65 years funded through the NDIS is worsening. They cannot utilise their support packages to access palliative care. Palliative care is viewed as a health matter rather than a disability service which requires recipients to engage separate providers. Specifically, issues that Palliative Care Australia has identified are:

- Widespread confusion about which services and systems are responsible for the provision of disability and other supports for people with life-limiting conditions.
- Limited options for people under 65 years of age diagnosed with life-limiting conditions who need support with daily living and other essential services, but who cannot access these from the NDIS or any other system.
- Inconsistencies in how the NDIS makes decisions about who can access the scheme, where the NDIS believes someone has 12 months or less to live.
- Inconsistencies in what services NDIS participants with a life-limiting illness can purchase with NDIS funds, once the NDIS becomes aware their life expectancy is limited.

It was agreed that this gap in support services is causing significant distress, especially people who are caught up in the disability sector who are experiencing additional complications not necessarily related to the disability but results in reduction of functionality. The group stipulated that the program must provide "agile care support provided in the home". This needs to be implemented as part of a discharge process. As part of the program introduction, it should assess the person's care needs and support network and look to incorporate formal and informal carers. At a system level change is required, building capacity at community level is also required. Initiatives like Compassionare Communities need to be developed to create personalised and sustainable support systems to allow people to live out their lives ideally in their home rather than being in hospital for an extended and indefinite term.

The group felt strongly that a mapping process, which is being conducted by WA Health, should be part of any new investment, and understanding the current initiatives within the local health system is vital. Programs like the WA Virtual Emergency Department (WAVED) impacts service delivery. See here:

<https://www.health.wa.gov.au/~media/Corp/Documents/Improving-health/WAVED/WAVED-Residential-aged-care-factsheet.pdf>

Finally, better education and connection with the National Disabilities Insurance Scheme (NDIS) and the sector is needed to help organisations recognise the changing needs of their clients when their health is changing and they are becoming palliative, as well as living with a disability.

Note:

- Silverchain offers in-home specialist palliative care clinical services already. The services that are not funded are non-clinical personal support services.

- WA Country Health Service palliative care program has palliative care support packages to enable access to home care services sooner, while awaiting government home care packages or NDIS, for those under 65 years. This enables patients accessing palliative care to be at home if that is their wish and have assistance with services they would otherwise get under a government home care package or NDIS, such as personal care, transport or respite. This is an interim package until a government home care package or NDIS is secured.
- Post meeting, a discussion with CarersWA identified a hospital-based program titled “Prepare to care hospital program” which may be of assistance in preparing the carer for the release of the patient, but establishing interim support packages consisting of care support and equipment is a complex process. https://www.healthywa.wa.gov.au/Articles/F_1/Going-to-hospital/Going-home-after-a-stay-in-hospital <https://www.carerswa.asn.au/our-services/prepare-to-care-hospital-program/#:~:text=The%20%E2%80%9CPprepare%20to%20Care%E2%80%9D%20Hospital,following%20being%20discharged%20from%20hospital>
- Hospital stay guidelines are attached which summarises the processes. Ultimately there is a need to problem solve! <https://www.health.wa.gov.au/~media/Corp/Documents/Health-for/Health-Networks/Disability/Hospital-Stay-Guidelines-Part-3.pdf>

Request for information ‘Election Ask’

WA State and Federal elections will occur in 2025. The WA State election will be held on 8 March 2025 and the Australian Government election is expected to be on or before on or before 27 September 2025.

PCWA will be preparing an ‘Election Ask’ for the WA election, and hence is seeking sector input. Please consider what your organisations sees as the pressing needs for palliative care in WA and email them to PCWA by 19 July 2024 via info@palliativecarewa.asn.au

Brief updates

Advance Care Planning (ACP)

The ACP education is conducted by Palliative Care WA to consumers via workshops, funded by the Department of Health, and the one-to-one ACP Support Service, which is available thanks to funding from Carers WA.

Compassionate Communities Australia

Compassionate Communities Australia (CCAus) was launched in late March by WA Governor Hon Chris Dawson at Government House in Perth.

Professor Samar Aoun, Dr Stephen Ginsborg, Dr Joanne Doran, and Harpreet Kalsi-Smith joined forces to create the national peak body, bringing their unique perspective including research, palliative care, primary care, community development and personal experience.

CCAus’s role will be to pioneer the development of Compassionate Communities across Australia.

The national not-for-profit organisation aims to become a hub of knowledge, skills and resources for community-led solutions that will lead to social and systems change.

To find out more about CCAust, visit [HERE](#).

National Palliative Care Week Breakfast

National Palliative Care Week will run from 19 to 25 May with the theme 'People at the heart of quality palliative care'. Our annual sector breakfast event will be on Tuesday 21 May with the topic 'Sharing the Care - Health professionals or community: which group comes first in a compassionate communities’ approach to care.' Our guest speakers include Dr Julian Abel and Professor Samar Aoun. As well, there will be a panel discussion with representatives from clinical and community backgrounds, including Dr Alison Parr, Gabriella Jerrat and Michelle Elson.

To book your place at this signature event visit [HERE](#)

Other activities during the week include:

- A Death Café – demystifying death on Thursday 23 May at Karrakatta Cemetery Cafe from 10.00am to 11.30am. To book visit [HERE](#)
- A Prepare to Care workshop on Monday 20 May at PCWA headquarters at 15 Bedbrook Place, Shenton Park from 10.00am to 12.00pm. To book visit [HERE](#).
- Hospital activations in association with PaSCE at Royal Perth Hospital, Fiona Stanley Hospital, and Fremantle Hospital.
- ACP workshops at Manning Library (open to the public) and Dementia Australia (not open to the public).

Attendees

- Professor Samar Aoun, Perron Institute Research Chair in Palliative Care UWA, Chair of Compassionate Communities Australia, and Chair South West Compassionate Communities Network (PCWA Board member)
- James Jarvis, CEO Busselton Hospice
- Renae Lavell, Executive Director Silver Chain Group
- Yasmin Naglazas, CEO Parkinson's WA (PCWA Board member)
- Dr Alison Parr, Clinical Lead Palliative Care, WA Department of Health
- Maria Davison, CEO Melville Cares Inc(PCWA Board member)
- Melanie Marsh, Cancer Information and Support Services Director, Cancer Council WA
- Donelle Rivett, Executive Manager Corporate Support and Projects, Bethesda Health Care
- Kelly Worlock, Chief Operations Officer, Brightwater Care Group
- Sophie Hennessey, GM Client Services, Dementia Australia
- Charlene Yates-Bishop, Board, Lionheart Camp for Kids
- Maeve Egan, CEO, MND WA
- Florence Humair, Clinical Nurse and Educator, Palliative Care Outcomes Collaboration
- Peter Mott, Ramsay Health Care, WA Government Relations Manager
- Pat O'Dal, Paramedic Practitioner Project Lead, St Johns WA
- Aja Styles, External Affairs Specialist, St Johns WA
- Lenka Psar-McCabe, CEO Palliative Care WA
- Jo Micallef, Administration and Events, Palliative Care WA
- Liz Rehfeldt, Marketing and Communications, Palliative Care WA

Apologies

- Dr Elissa Campbell, President Palliative Care WA
- Shelly Skinner, CEO and Founder, Lionheart Camp for Kids
- Jane Edmond, Chief Supported Accommodation Officer, Rocky Bay
- Ashley Reid, CEO Cancer Council WA,
- Professor Davina Porock, Research Fellow, School of Nursing and Midwifery, ECU (PCWA Board member)
- Daniel Heredia, Group Executive Insurance and Health Services, HBF
- Fiona Jane, Clinical Hospice Manager, Albany Hospice
- Daniel Hitchcock, Director Corporate Services, Hall and Prior
- Brian Pyne, Group Chief Executive Officer, St John of God Health Care