



## **CEO Roundtable for Palliative Care – Meeting held on 19 March 2025**

### **Communique 11**

At our March CEO Roundtable for Palliative Care meeting, 22 representatives from organisations with an interest in palliative care met to discuss latest developments in palliative care in the State.

Topics discussed included the following:

#### **Topic 1: The WA Law Reform Commission's review of the Guardianship and Administration Act (GAA).**

The commission released for public comment a discussion paper in two volumes outlining the current law in Western Australia and possible ideas for change. PCWA was asked to be part of the WA Law Reform Commission's Older Persons Reference Group.

The Act requires guardians and administrators to act according to their opinion of the best interests of the represented person (s51 and 71).

The commission asked: What does this mean? Should the Act consider 'Supportive Decision-making' instead of the current system which is based on 'Substitute Decision-making' appointments of guardians. Noting that the Australian Law Reform Commission Report and the Disability Royal Commission recommended that Australian guardianship laws incorporate a formal supporter model. Should there be legislative recognition that people may have fluctuating 'decision-making abilities' and the need for flexibility to reflect this – including time of day for assessments, environment and provision of information to person being assessed?

Discussion among the group centred on:

- The need to consider a human-rights based approach to changes to the Act.
- The risk of Enduring Power of Guardianship being frequently misused and coming into effect too soon for some individuals and the Act being important to help ensure people's rights are maintained.
- The complications caused by a slow State Administrative Tribunal (SAT) process.
- The importance of supportive decision-making to protect people's rights to determine their lifestyle choices.
- Supportive decision-making is favourable in concept but there was concern expressed by service providers on how this is practically implemented.
- The importance of allowing people to live a life according to their wishes, with the term used being 'the dignity of risk' as opposed to a low risk tolerance. Managing that balance is challenging especially with ageing and fragmented families.
- Fluctuating decision-making abilities can be difficult for carers as in the case of dementia – people can be cogent one day but not the next.
- The inherent paternalism of the health system can make supportive decision-making challenging.
- There is often a cultural overlay to be considered which service providers have to navigate.
- The group was also cognisant of the possibility of coercion occurring at the home.
- Consideration that the language used in the Act be 'humanised' and that supportive decision-making would be welcomed to provide a better quality of care aligned to the wishes for their life of the person under the guardianships, noting that often there is a balancing act between freedom versus protection.

The sector is encouraged to make their own submission to the Law Reform Commission of Western Australia – <https://www.wa.gov.au/government/announcements/discussion-paper-volume-one-project-114-guardianship-and-administration>

## **Topic 2: New Aged Care Act – greater emphasis on end-of-life (EoL) support**

Attendees at the meeting discussed what information the palliative care sector wants to convey about the services they deliver for EOL to support the aged care sector.

Discussion centred around Palliative Care Australia's (PCA) draft submission on Support at Home End of Life Pathway.

The draft position statement states:

PCA welcomes the Australian Government's September 2024 announcement that the *Support at Home* aged care program will include a short-term End-of-Life Care Pathway.

This is a significant and positive reform, consistent with strong community preference to receive both aged care and palliative care at home for as long as possible with appropriate support. Like any major reform there will be implementation challenges that must be managed for the Pathway to be a success; this document describes some of the likely challenges and provides suggestions to address these.

Given the scale of the reform, PCA recommends the Pathway undergo independent evaluation one year after commencement to ensure it is achieving its stated intent.

Recommendations in the paper include:

- Needs-based rather than prognosis-based, eligibility would better support the pathway's intent and the right to palliative care set out in the *Aged Care Act 2004*.
- PCA recommends that time limits on participation in the Pathway be removed, for those assessed as eligible. This will ensure that those who are eligible to participate in the Pathway can continue to access the additional end-of-life supports until they die, without potential interruption or reduction in services. This approach would recognise the variability of end-of-life illness trajectories and be consistent with the right to equitable end-of-life care set out in the *Aged Care Act 2024*. It is also consistent with the approach in residential care, where people who enter in order to receive planned palliative care must have an estimated life expectancy of 3 months or less but can continue to access supports under AN-ACC Class 1 until their death.
- Given the scale of the reform, PCA recommends the Pathway undergo independent evaluation one year after commencement, to ensure it is achieving its stated intent. It will be important to confirm which of above objectives will be tested through evaluation

CEO Roundtable participants believed PCA's draft position statement was very sound.

Discussion centred around:

- The nature of the \$25k Support at Home aged care program was that it was not a lump sum payment but rather an uptick in extra supports up to \$25k.
- Existing home care package would pause while 16-week package was in place.
- Could not be used for services already available in the State, that is, not a cost-shifting exercise.
- People's varying opinions about wanting to die at home or not at home.
- A lot of people want to live at home as long as possible until it was no longer possible.

- Concern about the length of time to assess eligibility – could take up to three months.
- Concern about risk from changes to what is eligible, especially medicine management and personal care.

## **Tributes**

The attendees at the meeting wanted to pay tribute to two key leaders for their services to supporting the aged care industry and creating service support system allowing people to live well as they age.

Vale Dr Penny Flett AO, who had a remarkable career spanning medicine, military service, research and advocacy, with a lifelong dedication to improving the lives of older Australians and people with disabilities. Penny was Brightwater's Chief Executive Officer for two decades and shaped the organisation as well as the industry.

Vale to Mary Lonergan, co-founder of White Oak now part of Hall and Prior.

## **Meeting attendees**

- Dr Elissa Campbell – Chair Palliative Care WA – meeting facilitator
- Lenka Psar-McCabe, CEO Palliative Care WA
- Marnie Chellew-Hawley, Principal Policy Officer Palliative Care, WA Department of Health
- Dr Margherita Nicoletti, Clinical Lead End of Life Care, WA Department of Health End of Life Care Program
- Barbara Voight, Nurse Educator, Palliative Care, NMHS
- Samar Aoun, Compassionate Communities Australia, Perron Institute
- Donelle Rivett, Executive Manager Corporate Support and Projects, Bethesda Health Care
- Duncan Guy, CEO Senses WA
- Tanya Pidgeon, Facilitator, PCOC
- Fiona Simpson, State Manager Client Services, Dementia Australia
- Liz Behjat, State Manager WA and NT, Ageing Australia
- Mark Kinsela, CEO, COTAWA
- Richard Newman, CEO, Carer's WA
- Catherine Stoddart, CEO, Brightwater Care Group
- Janelle McFarlane, Director Health Services, Silverchain
- Yasmin Naglazas, CEO, Parkinson's WA
- Etta Palumbo, CEO, Neurological Council of WA
- Fiona Simpson, State Manger Client Services, Dementia Australia
- Lyndall McFarlane, St John of God Health Care
- Yvonne Timson, CEO, Community Vision
- Jo Micallef, Partnerships, Events and Administration, Palliative Care WA
- Liz Rehfeldt, Marketing and Communications, Palliative Care WA

## **Apologies**

- Dr Neale Fong
- Yvonne Timson
- Dr Alison Parr
- Renae Lavell
- Henrietta Podgorska
- James Jarvis
- Maeve Egan
- Daniel Hitchcock