



Palliative Care
Western Australia
Living, dying & grieving well

Palliative Care WA State Government Election 2025

**Sustainable palliative care for all
Western Australians**

Palliative Care WA

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Sustainable palliative care for all Western Australians

Palliative Care WA is calling for all political parties to commit to investing in palliative care to meet the increasing demand for quality palliative care in Western Australia.

Palliative care and end-of-life care are integral parts of the health care system which improves the quality of life of patients with life-limiting illnesses and conditions, their families and carers, helping them to live, die and grieve well.

End-of-life and palliative care has been a major focus of the WA Government as highlighted by the Sustainable Health Review (SHR), the WA End-of-Life and Palliative Care Strategy 2018–2028 (the WA Strategy) and the reports from two Parliamentary Joint Select Committees (End of Life Choices My Life, My Choice report, JSCEoLC, and Palliative Care in Western Australia – Progress Report, JSCPC). The Parliamentary reports highlighted many gaps and barriers, particularly for rural and remote Western Australians, in accessing high quality end-of-life care and requiring system-wide changes.

As the peak body for palliative care in Western Australia, Palliative Care WA has canvassed sector organisations in Western Australia to develop this document outlining what we see as the essentials for the sustainability of quality palliative care in Western Australia. The recommendations in this document align and complement those of our national organisation, Palliative Care Australia, and state and territory palliative care organisations.

About Palliative Care WA

Palliative Care WA is the peak body for the palliative care sector across Western Australia. The organisation's Vision is that all people with life-limiting illnesses or conditions, and those important to them, are supported to live, die and grieve well.

A member-based, not-for-profit organisation, our Mission is to support and strengthen the collective voice and impact of the palliative care community, including people with a life-limiting illness or condition and those important to them, carers, health care professionals, volunteers, government and other organisations.

Our work is guided by a set of key values:

- Compassion – we see people as being at the centre of everything we do
- Respect – we are considerate of people and their choices
- Collaboration – we achieve positive outcomes through inclusive engagement, strong relationships, and respecting the role we play in supporting people and the sector.

Our **Strategic Plan 2024-2027** guides the direction and focus of the organisation and provides a road map for achieving our vision that all people with life-limiting illnesses or conditions, and those important to them, are supported to live, die and grieve well.

We do this by:

- Empowering the community
- Being a voice for the palliative care sector
- Developing the sector.

Our organisation represents the following member organisations:

- Aboriginal Health Council of WA
- Albany Community Hospice
- Ambulance Wish Western Australia
- Bethesda Health Care
- Brightwater Care Group
- Busselton Hospice Care Inc
- Cancer Council WA
- Carers WA
- Centre for Research in Aged Care, Edith Cowan University
- Dying With Dignity WA
- Hall and Prior
- Health Consumers' Council WA
- Kimberley Palliative Care Service
- Lionheart Camp for Kids
- LJM Memorial Hospice
- Melville Cares Inc
- Motor Neurone Disease Association of WA
- Silver Chain Group
- St John Ambulance WA
- St John of God Healthcare

Palliative care improves the quality of life of patients with life-limiting illnesses and conditions, their families and carers, helping them to live, die and grieve well.

Recommendations

RECOMMENDATION 1

Increase access to palliative care support packages for Western Australians under 65 years.

The funding commitment sought from the WA Government for this recommendation is for interim funding to be provided until a permanent resolution is negotiated with the Australian government. Program to be based on the WA Country Health Service (WACHS) palliative care packages, extending to the metropolitan area and permanently funding the WACHS program.

PCWA recommends increasing access to palliative care services for those under 65 years, including both National Disability Insurance Scheme (NDIS) participants and those ineligible for NDIS support.

We ask that the State Government negotiates with the Australian Government to expand access to social care supports to individuals under 65 requiring palliative care who are ineligible for NDIS support.

Issue: NDIS gaps that impact patients who have changing health needs

Unfortunately, the NDIS framework is not designed to assist individuals under 65 years experiencing functional decline due to life-limiting illnesses. Palliative Care Australia's 2024 Federal Budget submission, called for the Australian Government to establish an interim program until a permanent solution could be reached (estimated at \$65m for three years) for non-clinical care and support for people under 65 living with a life-limiting illness, including those with a disability, who need support with the activities of daily living to remain at home and out of hospital or those that are being discharged from hospital.

Issue: Under 65 gaps for those ineligible for NDIS

Support is required for people who are under 65 years, ineligible for NDIS support and fall ill requiring 24-hour, seven-days-a-week, 365 days-a-year care within the community. We ask the WA Government to negotiate with the Australian Government to:

- Expand access to social care supports to individuals under 65 years requiring palliative care and experiencing functional decline so that they can be released safely from hospitals into the community.
- Build local community support for these people and their families to provide care.

In the Perth metropolitan area, Silverchain provides clinical support, but it is not contracted to provide palliative clients who are waiting to receive government support with personal care, domestic assistance, transport or respite. A lack of these supports greatly impacts on a person's ability to remain at home at the end of life when they are unable to perform essential daily living tasks.

WACHS currently provides palliative care support packages to enable those under 65 years to access home care services. These support packages are provided on an interim basis until a home care package (HCP), or NDIS is secured and are specifically for non-clinical personal support services.

These interim non-clinical support packages should be extended, and an initial program trialled for the metropolitan area.

RECOMMENDATION 2

Continued and increased access to palliative care support funding for Western Australians accessing aged care.

A funding commitment sought for people in aged care facilities and in the community for specialist palliative care through access to training and support for workers in the industry. Noting aged care services are delivered in residential facilities, at home in the community and in retirement villages/seniors housing settings.

Palliative Care WA recommends:

- Creating improved understanding of measures being introduced, such as WA Virtual Emergency Department (WAVED). Advocating for improved timely access to federally funded support-at-home services and where there is a current failure in the system, fund interim support packages for people who are being discharged from hospital.
- Continued dialogue with the aged care sector, both residential and home care, regarding the need to develop an integrated strategy that brings together existing resources and services to maximise awareness and access. This will help reduce the risk of people 'falling through the gaps' and reduce extended hospital stays.
- Funding be provided for further training at the grassroots level on how the WAVED program works with community and residential aged care.
- Continued expansion of the Metropolitan Palliative Care Consultancy Service (MPaCCS).
- Increased support to palliative care services for those over 65 years, for both residential and home care recipients. Discussing and planning for a person's preferred end of life is complex and needs dedicated time and specialist skills. PCWA advocates for a dedicated service to aged care recipients for advance care planning that is then signed off by the person's GP and shared with providers to support its execution. For the majority of older people needing support who remain living at home

(over 80 per cent of those in receipt of aged care funding), the Australian Government-funded aged care packages often take a long time to be reassessed. These time frames fail to accommodate the changing needs of the person who has been admitted into hospital care. State-funded Specialist Palliative Care programs provide medical support but not interim care support packages until the person's ACAT is adjusted.

RECOMMENDATION 3

Improve community pharmacy support and services.

Funding commitment needed from the WA Government for this recommendation is to be determined based on consultation with the pharmacy sector.

PCWA recommends funding be allocated to:

- ensure availability and supply of necessary medications in palliative care settings, including regional, rural and remote areas.
- introduce dedicated palliative care training programs for community pharmacy workers to develop knowledge and increase support for people in the community.
- continue advocating for enhanced pharmacy support and services that focus on meeting the palliative care needs of people in the community regardless of their location across WA.

Palliative care pharmacy expertise is an area of specialisation that is significantly under-provided across WA Health. In rural areas, there is no specialist practitioner and WACHS pharmacist FTEs are already at the lowest level in Australia, resulting in an area of need for FTE growth.

Palliative care practice routinely involves the use of high-risk medications (e.g. opioids, sedatives), special access or off-licence medications. Safe prescription, dispensing, storage and disposal of medicines for community patients and partnership in the safe, quality use of medications are key requirements for the regional palliative care teams and to provide a more complex specialised service.

There is currently no WACHS pharmacy capacity to develop and participate in high-risk drug utilisation evaluation, quality assurance, research work and palliative care education programs for pharmacists, or assist in pharmacy graduate and undergraduate, nursing, medical and other palliative care training programs.

RECOMMENDATION 4

Increase funding for community education and the education of health care professionals.

Funding commitment required from the WA Government for palliative care education to be continued, a trial for the expansion of 1-1 Advance Care Planning, and home care staff training on signs of dying undertaken.

PCWA recommends that increased funding be allocated to:

- Palliative Care WA to continue to provide community workshops on advance care planning, palliative care and grief and loss
- enable Palliative Care WA to reintroduce the one-to-one ACP Support Service to assist community members to complete their Advance Health Directives and other ACP documentation, including Enduring Power of Guardianship

- Palliative and Supportive Care Education (PaSCE) to continue to provide education to health professionals and volunteers involved in the delivery of palliative care in hospitals and aged care facilities
- creation of new funding for education of health professionals and volunteers involved in the delivery of care in home care, and understanding the signs of dying.

Independent research has shown that PCWA's theoretical-based ACP workshops are effective in supporting completion of Advance Health Directives (AHD) and/or Enduring Power of Guardianships (EPG) as well as increasing participants' knowledge of ACP concepts (Haywood et al, 2022).

ACP gives a range of benefits to an individual, their family, health professionals and the health system, including:

- increased satisfaction with end-of-life care
- increased access to appropriate palliative care
- less stress, anxiety and depression for the family
- lower health expenditures (Buck et al, 2021; Haywood et al, 2022; PCA & KPMG, 2020).

Advance care planning generates savings in the health system by reducing:

- the rate of hospitalisation and length of stay in the last year of life
- the admission to intensive care units by 37 per cent
- unnecessary calls to emergency services and subsequent admissions to emergency departments in nursing home residents by around 20 per cent (PCA & KPMG, 2020).

PCWA delivered 268 face-to-face and online workshops to 5,840 participants during the years 2020 to June 2024. Ninety-nine per cent of participants over this time indicated that the workshops were useful to them and that they would recommend the workshops to others.

Workshops were delivered in metropolitan Perth as well as regional areas, including the Kimberley, Pilbara, Wheatbelt, Goldfields, Midwest and South West. Workshops were delivered to community members in varied contexts, including libraries, men's sheds, retirement villages, learning centres, local governments and via the offices of parliamentarians.

Workshops were delivered to priority groups, including people with CaLD backgrounds, Aboriginal people, people experiencing cognitive decline, people with disabilities, people living with life-limiting conditions such as cancer and MND, the LGBTQI+ community, and carers.

Cancer Council WA's Palliative and Supportive Care Education program (PaSCE) comprises five education streams for health professionals and volunteers – Professional Development Education, Residential Aged Care Excellence in Palliative Care Communicate (RACEPC), Program of Experience in Palliative Approach (PEPA), Volunteer Education and Post Graduate Scholarships.

PaSCE collaborates with experienced palliative care clinicians to develop evidence-based education that enhances knowledge and confidence in delivering optimal palliative care across all healthcare settings. Over a six-month period in 2024, PaSCE delivered education to more than 1,038 people. With increased financial support, PaSCE would expand to deliver comprehensive education that aligns with industry needs. PaSCE could design and deliver training programs for home care staff, improving their death literacy and capacity to care for people who wish to die at home.

RECOMMENDATION 5

Grow initiatives that educate and engage the community to build compassionate communities.

On-going funding commitment is needed from the WA Government for building the capabilities of compassionate communities to support formal carer services.

PCWA recommends that increased funding be made available to promote community-centric initiatives aimed at educating, engaging and empowering people to foster compassionate communities.

On-going, increased funding would:

- increase community engagement by developing and implementing initiatives that engage community members in understanding and supporting palliative care at grassroots by building capacity through compassionate communities.
- invest in educational initiatives which enhance death literacy and empower people to create compassionate communities, to support those experiencing life-limiting conditions, dying, death, caregiving and grief.
- build compassionate communities to forge partnerships between local organisations, especially Local Government Authorities, and community organisations such as LinkWest, to grow a network of support for compassionate care initiatives.
- increase funding for the compassionate communities' model, that allows the introduction of coordinators to help liaise with palliative care services.

Compassionate communities are essential for well-being. Research shows that the influence of social relationships on mortality risk is comparable with well-established risk factors, such as smoking and alcohol use (Holt-Lunstad & Layton, 2010). A public health approach to palliative and end of life leads to better outcomes for community members as well as significant cost savings from reduced hospital usage (Aoun et al, 2021).

Note: PCWA has undertaken a WA Primary Health Alliance (WAPHA) project with LinkWest to build capacity at 26 centres around ACP, palliative care, death literacy and grief.

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