



2024-26

PRIORITIES

FOR PALLIATIVE CARE IN SOUTH AUSTRALIA

We are inclusive.

We celebrate multiple approaches and points of view.

*When we say palliative care is everybody's business,
no matter their age, we mean everybody.*

ACKNOWLEDGEMENTS

Our organisation acknowledges the Traditional Custodians of the lands and seas on which we live and work, and pays respect to Elders - past, present and emerging.

Palliative Care South Australia wish to thank all our staff and board members who have supported the development of this document and our stakeholders, Summit speakers and PCSA members who have given their valuable time and expertise to help guide the development of this publication, Carol Hope Consulting for your assistance in theming the information.

We greatly appreciate the contributions everyone has made in sharing experience, knowledge and time with us.

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BACKGROUND

BACKGROUND

About Palliative Care South Australia

Palliative Care South Australia (PCSA) is a leading charity and independent peak body representing palliative care providers, the community and people experiencing a serious illness, dying, death and grief, as well as those with an interest in palliative care across South Australia.

Our belief: The way we care for our dying reflects the humanity and compassion of our society

Our mission: To promote quality palliative care and access for ALL through advocacy, information provision and education to build capacity and service responsiveness

Our strategic priorities: We support all South Australians to:

- Live well every day until their last
- Have a dignified death, regardless of illness, age, culture, religion, gender, sexuality or location
- Advocate for holistic, quality and culturally appropriate palliative care
- Nurture supportive social networks at the end stages of life

About Palliative Care South Australia's Biennial Summit and Priorities for Palliative Care in South Australia publication

“

“PCSA represents the collective voice for the palliative care sector in SA. The Summit, consultation and this publication provide an advocacy framework for PCSA, our Members, the palliative care sector and the South Australian community.”

– Ms Susan Emerson, Chair Palliative Care South Australia

PCSA hosted its first Summit in 2023. The purpose of this Summit was to bring together people with a key interest in Palliative Care in South Australia, to discuss learnings, build connections and identify sector priorities.

This is the first Palliative Care in South Australia Priorities publication. The purpose of this publication is to share the outcomes of the Summit and sector consultation, to provide a tool for the South Australian Palliative Care sector to identify strategy, policy and actions for the following years.

“

“PCSA recognises that there are limited resources in the palliative care sector therefore by identifying and publishing biennial priorities for the sector we hope that we can help provide direction for those limited resources. In doing so, creating a collective effort focusing on specific priorities and focus areas related to common hot topics.”

– Adjunct Associate Professor Shyla Mills, CEO Palliative Care South Australia

HOW THE 2024-26 PRIORITIES AND HOT TOPIC KEY IMPROVEMENT AREAS WERE DEVELOPED

The Palliative Care South Australia Summit 2023

The Palliative Care South Australia Summit is a biennial event that includes both State and National experts and service representatives speaking.

The Summit took place on the 26th June 2023 where representatives from the following organisations participated:

- Palliative Care Australia
- Australian New Zealand Society of Palliative Medicine
- Palliative Care Nurses Australia
- Paediatric Palliative Care Australia and New Zealand
- Palliative Care Social Workers Australia
- Public Health Palliative Care International
- Grief Australia
- Department for Health and Wellbeing
- Palliative Care South Australia
- CEIH: SA Palliative Care Clinical Network
- Northern Adelaide Palliative Care Service
- Central Adelaide Palliative Care Service
- Southern Adelaide Palliative Care Service
- SA Paediatric Palliative Care Service
- Adelaide Primary Health Network
- Country SA Primary Health Network
- University of Adelaide
- Flinders University
- University of South Australia

We asked each of these representatives to focus on the following three areas in their presentation:

- Tell us about your organisation
- Tell us how you benefit South Australians
- Tell us your recommendations for the top 3 priorities for Palliative Care in SA

Over 150 people from a diverse range of backgrounds and organisations attended or viewed online afterwards.

Priorities theming, ranking and finalisation

The findings from the Summit activities were analysed by a consultant and a draft version of the Palliative Care in South Australia Priorities 2024-26 was created. This draft version was reviewed by Department for Health and Wellbeing representatives, SA Health CEIH Palliative Care Clinical Network leads and the PCSA board, then sent to PCSA members for feedback and ranking. The document was revised to reflect feedback and then reviewed and approved by the PCSA Board in April 2024.

Process of development

The Priorities of the Summit presentations were collated and a Thematic Analysis Report was created which presents the common themes identified throughout the presentations and their ranking by number of mentions.

Figure 1: Analysis Methodology



It is important to acknowledge that number of mentions may not accurately represent the actual level of priority for each theme, due to the following observations from the analysis:

- Several organisations presented their priorities based on their own purpose / strategy rather than the priorities specifically for the South Australian context. This was particularly the case for the national / peak body groups.
- The presenters represented their sectors / jurisdictions, and their priorities may reflect specific issues within those jurisdictions.
- Many of the themes and subthemes overlap. For example, several presenters identified care in the community setting as a priority. Some presenters identified more funding for community care to be a priority and others identified improving access as the priority.

Priorities identified themes

The analysis identified six themes across the stakeholder priorities. A theme in this analysis is a priority that was mentioned at least five times across the presentations. Each of the themes have subthemes which provide greater context. The subthemes are areas which were mentioned / identified more than once within a theme.

A mapping process was then undertaken to review the priorities and subthemes against other key strategic and publications including:

- South Australia's Palliative Care Strategic Framework 2022-2027
- Federal Government's Implementation plan for the National Palliative Care Strategy (2018)
- Palliative Care Australia's National Palliative Care Standards (5th Edition 2018)
- Palliative Care Australia's National Palliative Care Standards for all health professionals and aged care services (2022)

This background mapping paper is available on the PCSA website.

Priorities ranking and finalisation

PCSA members were then invited to rank the identified priorities and their top two key improvement areas via a survey, over 50 people responded.

Hot Topics theming, ranking and finalisation

In addition to The Priorities identified throughout The Summit, a list of Hot Topics were identified through discussions with palliative care leaders across South Australia. A survey was then sent to Palliative Care SA members, E-news subscriber list and promoted on social media asking people to identify and rank focus areas related to each Hot Topics. Over 40 people engaged in the survey and this is a summary of these results.

PEOPLE
AT THE HEART OF
PALLIATIVE CARE
2024-2026

PEOPLE AT THE HEART OF PALLIATIVE CARE

“

PCSA agrees with the SA government's Palliative Care Strategic Framework 2022-2027 vision: "All South Australians, their families and carers [should] have access to and receive the best possible end of life and palliative care that places the person at the centre of care and supports them to live and die well in accordance with their individual needs, wishes, values and preferences." ¹

Why is there a growing need for palliative care in SA?

- ♥ **South Australia has one of the longest life expectancies in the world²**
Increased longevity of South Australians contributes not only to a higher number of older people in the population, but also a change in the nature of diseases together with the time and the way that people die
- ♥ **Society as a whole is still reluctant to discuss dying which is impacting outcomes**
People with high levels of death literacy have context specific knowledge about the death system and the ability to put that knowledge into practice³
- ♥ **South Australia's population is metropolitan centric⁴**
People living in rural and remote areas have reduced access to specialist care

How does palliative care impact South Australians?

Approximately



South Australians a year could directly benefit from palliative care services

75% of deaths in South Australia would benefit from palliative care^{5,6}

Approximately



South Australians a year are directly affected by someone close to them dying from a life-limiting illness

On average 9 people are directly affected by someone's death⁷

100%



of South Australians will be impacted by death and dying

PCSA agrees with KPMG:

"There is a clear economic case for increased investment in palliative care in Australia"⁸

What can we do?

- ♥ Invest to save⁸
- ♥ Utilise the Priorities for Palliative Care in SA 2024-2026

PRIORITIES
FOR PALLIATIVE CARE
IN SOUTH AUSTRALIA
2024-26

2024-26 PRIORITIES

FOR PALLIATIVE CARE
IN SOUTH AUSTRALIA

1 **FUNDING** 

2 **WORKFORCE** 

3 **ACCESS** 

4 **PUBLIC HEALTH
APPROACHES TO
PALLIATIVE CARE** 

5 **INFORMATION
AND RESEARCH** 

2024-26 PRIORITIES

FOR PALLIATIVE CARE IN SOUTH AUSTRALIA

FUNDING



Providing care in a person's place of choice is a critical component of excellent palliative care. To meet this, it is a priority to focus on funding.

KEY FOCUS AREAS FOR THIS PRIORITY

- » Increase funding for palliative care in home / in the community
- » Increase all aspects of funding to palliative care across South Australia to meet needs



2024-26 PRIORITIES

FOR PALLIATIVE CARE IN SOUTH AUSTRALIA

2 WORKFORCE

A quality palliative care interdisciplinary team is a critical component of excellent palliative care. To meet this, it is a priority to focus on workforce.

KEY FOCUS AREAS FOR THIS PRIORITY

- » Support capacity and capability building in relation to the palliative care workforce
- » Focus on workforce retention



2024-26 PRIORITIES

FOR PALLIATIVE CARE IN SOUTH AUSTRALIA

3 ACCESS

Access to palliative care when and where people need is a critical component of excellent palliative care. To meet this, it is a priority to focus on access.

KEY FOCUS AREAS FOR THIS PRIORITY

- » Increasing access to community (home-based) palliative care
- » Improving access for underserved populations (including people under 65, people in country areas, caregivers, people with uncertain prognosis)



2024-26 PRIORITIES

FOR PALLIATIVE CARE IN SOUTH AUSTRALIA

4 PUBLIC HEALTH APPROACHES TO PALLIATIVE CARE

Recognising the community as an equal partner is a critical component of excellent palliative care. To meet this, it is a priority to focus on public health approaches to palliative care.

KEY FOCUS AREAS FOR THIS PRIORITY

- » Co-design models with consumers and improve consumer engagement
- » Integrating public health approaches in palliative care policies, systems and projects



2024-26 PRIORITIES

FOR PALLIATIVE CARE IN SOUTH AUSTRALIA

5

INFORMATION AND RESEARCH



Strong evidence, quality data and research are critical components of excellent palliative care. To meet this, it is a priority to focus on information and research.

KEY FOCUS AREAS FOR THIS PRIORITY

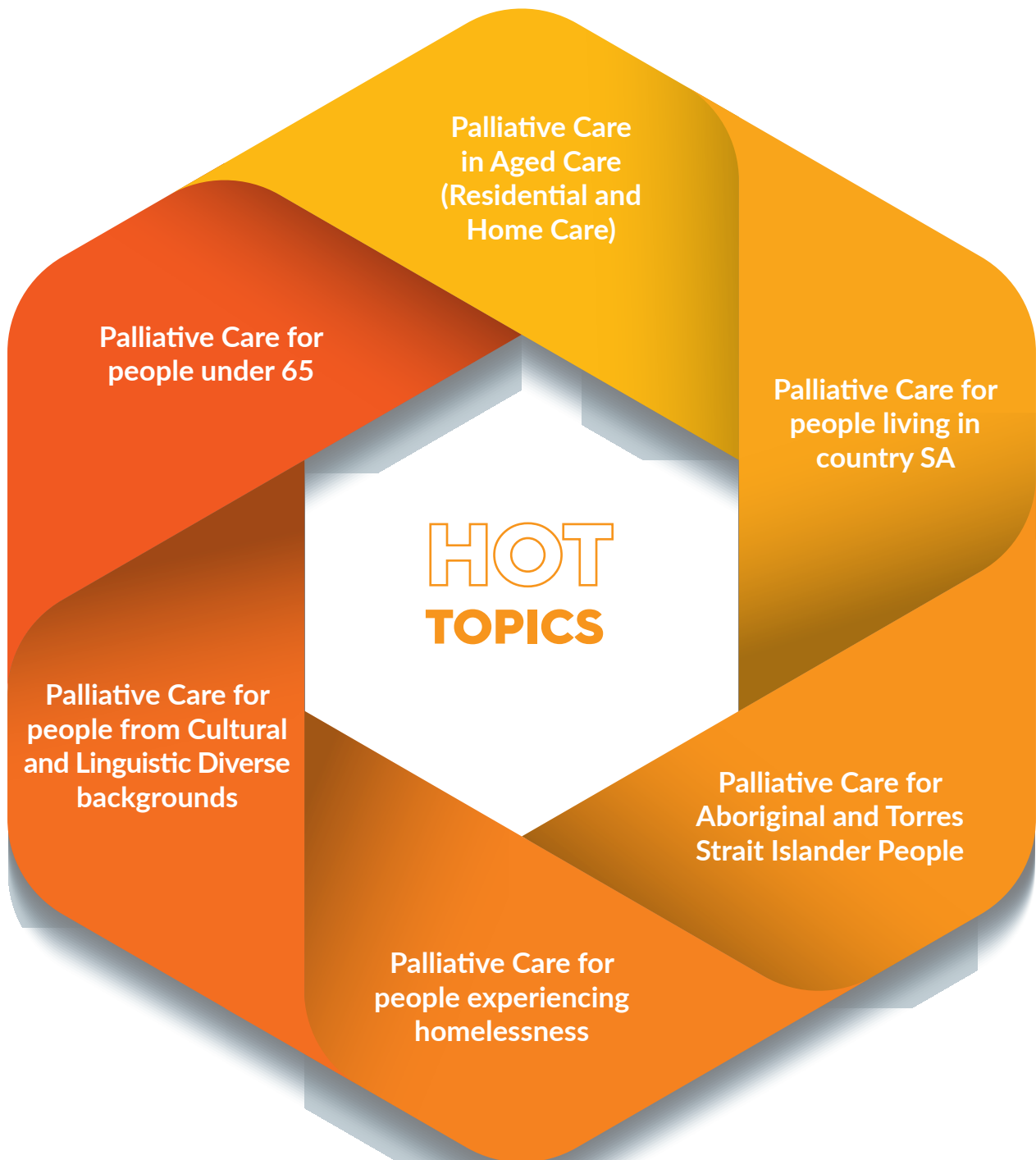
- » Improving data collection
- » Build evidence and research



PALLIATIVE CARE
HOT TOPICS
2024-26

2024-26 PRIORITIES

FOR PALLIATIVE CARE IN SOUTH AUSTRALIA



HOT TOPICS

In addition to The Priorities, Hot Topics are specific focus areas for palliative care. Focus Areas for each of these Hot Topics are identified below.

PALLIATIVE CARE IN AGED CARE

(RESIDENTIAL AND HOME CARE)

FOCUS AREAS FOR THIS HOT TOPIC

- » More responsive end-of-life care by multidisciplinary care teams for older people
- » Ensure access to My Aged Care (MAC), for assessment and approval for care and services at home is timely for people with palliative care needs
- » Longer respite options
- » Increase the variety of options of respite for older people with palliative care needs, and ensure timely access

PALLIATIVE CARE FOR PEOPLE LIVING IN COUNTRY SA

FOCUS AREAS FOR THIS HOT TOPIC

- » Increase metro multidisciplinary palliative care specialists visits
- » Access to face-to-face clinical support out of hours for community based palliative care clients
- » Inclusion of pharmacist in all country palliative care teams

PALLIATIVE CARE FOR ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLE

FOCUS AREAS FOR THIS HOT TOPIC

- » Increase the provision trauma informed palliative care services that are flexible and responsive
- » Prioritise systems to assist people to return to country at the end of life, if that is their wish
- » Increase cultural awareness training for palliative care staff

PALLIATIVE CARE FOR PEOPLE EXPERIENCING HOMELESSNESS

FOCUS AREAS FOR THIS HOT TOPIC

- » Access to safe housing for people with a life-limiting illness
- » Palliative care support packages for people under 65 years of age
- » More education/support for all staff in engaging with vulnerable populations

PALLIATIVE CARE FOR PEOPLE FROM CULTURAL AND LINGUISTIC DIVERSE (CALD) BACKGROUNDS

FOCUS AREAS FOR THIS HOT TOPIC

- » Provide appropriate information in multiple languages
- » Increase cultural awareness training for palliative care staff
- » Increase CALD community consumers engagement with palliative care

PALLIATIVE CARE FOR PEOPLE UNDER 65

FOCUS AREAS FOR THIS HOT TOPIC

- » Create rapid access and flexible palliative care supports and equipment packages for people under 65 years of age
- » Provide better respite (or residential living spaces) that are not aged care facilities for people under 65 years of age
- » Increase uptake and awareness of Advance Care Planning for people under 65 years of age

CALL TO ACTION
DISSEMINATION
AND ACTIVATION
OF THE PRIORITIES

“

“The huge costs associated with death are not inevitable... Investment into palliative care can deliver lower end-of-life costs to Government at the same time as achieving positive health and social outcomes for people experiencing life-limiting conditions.”

– KPMG, 2020⁹

CALL TO ACTION: DISSEMINATING AND ACTIVATING THE 2024-26 PRIORITIES

The Priorities for Palliative Care in South Australia 2024-26 were created by the sector, for the sector. These priorities were developed following a robust process of consultation. They provide direction for the sector that supports much needed transformation of South Australia’s palliative care system.

To become involved in promoting the priorities, please consider the following possibilities for action:



Individual Actions

- Engage your personal networks, local community and community groups
- Talk to your local Member of Parliament (MP) and local Council



Organisational Actions

- Include the priorities in your organisational strategic, operational and improvement plans
- Create working groups to enact the priorities



Government Actions

- Make the case for palliative care system improvements in the legislature and in committee work
- Use the priorities to guide government actions, election commitments and policies



Share your actions/improvements with your networks, on social media and/or with Palliative Care South Australia.



facebook.com/PalliativeCareSA



linkedin.com/company/palliative-care-south-australia

Learn more here: www.palliativecaresa.org.au/priorities-for-palliative-care-in-sa

SUPPORT PALLIATIVE CARE SOUTH AUSTRALIA TO CONTINUE TO HOST THE BIENNIAL SUMMIT AND DEVELOP THE PRIORITIES FOR PALLIATIVE CARE IN SOUTH AUSTRALIA

Sponsor our Biennial Palliative Care in South Australia Summit



Contact our team to discuss sponsorship opportunities for our Biennial Summit event: hello@palliativecaresa.org.au

Make a tax-deductible donation to Palliative Care South Australia



All donations over \$2 are tax deductible. Please help PCSA to educate and advocate for South Australians to live, die and grieve well.

Donations can be made at www.palliativecaresa.org.au/donations

Become a member of Palliative Care South Australia



Membership of Palliative Care South Australia is available to individuals or organisations who have an interest in palliative care in South Australia.

Join today: www.palliativecaresa.org.au/membership

Join the PCSA Volunteer Village



It doesn't matter your age, skill or cultural background. All you need is a passion for helping out peak body activities that support South Australian's to live, die and grieve well.

Learn more here: www.palliativecaresa.org.au/become-a-volunteer

SOURCE INFORMATION

1. Government of South Australia (2022). South Australia's Palliative Care Strategic Framework (2022-2027).
2. Rosenwax et al. (2016). A retrospective population-based cohort study of access to specialist palliative care in the last year of life: who is still missing out on a decade on? BMC Palliative Care.
3. Leonard, R., Noonan, K., Horsfall, D., Psychogios, H., Kelly, M., Rosenberg, J., Rumbold, B., Grindrod, A., Read, N., and Rahn, A. (2020). Death Literacy Index: A Report on its Development and Implementation. Sydney: Western Sydney University.
4. Palliative Care Outcomes Collaboration (2018). Patient outcomes in palliative care: South Australia, July - December 2017.
5. Australian Bureau of Statistics (2022). Deaths, Australia, ABS Website, accessed 25 January 2024.
[note estimation of 16,000 death rate for 2024-2026 period of this report is based on 2022 SA deaths 15,455, annual increase around 961]
6. Palliative Care Australia (2018). Palliative Care Service Development Guidelines. [note estimation based on: "It has been estimated that about 75% of all deaths are expected (such as people living with cancer or end-stage renal disease) and might benefit from the provision of palliative care"]
7. Pearce, C et al (2021).. 'A silent epidemic of grief': a survey of bereavement care provision in the UK and Ireland during the COVID-19 pandemic. BMJ.
[note estimation based on: "It is estimated that for every death, nine people are affected by bereavement"]
8. KPMG & Palliative Care Australia (2020) Invest to Save, The economics of increased investment in palliative care in Australia.

PALLIATIVE CARE SOUTH AUSTRALIA'S POLICY GUIDING PRINCIPLES

Palliative
Care is...

about the
whole person



for
every age &
every stage



about the
community
of care



about
choice, autonomy
& dignity



not
'one-size
fits all'



Everyone's
business



care for
the carer



a human
right



Palliative Care.
It's more than
you think.



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