National Palliative Care Week 19-25 May





Supporter toolkit



Introduction

About Palliative Care Australia

<u>Palliative Care Australia (PCA)</u> is the national peak body for palliative care. We represent all those who work towards providing high-quality palliative care for Australians.

We raise awareness about palliative care, improve access to palliative care services for people of all ages with life-limiting illness and support the workforce who play a critical role in providing quality care.

We encourage the Australian community to talk about and engage with conversations and planning surrounding life limiting illness, death and dying.

Our members around Australia are key to this work.

About Palliative Care

Palliative care is high quality health care and support for people living with a life-limiting illness and their families. Palliative care is holistic and helps people to live as well as they can by managing pain and symptoms to ensure their quality of life is maintained as the illness progresses.

Palliative care identifies and treats symptoms and issues associated with life-limiting illness which may be physical, emotional, spiritual or social. Palliative care is a family-centred model of care, meaning that family, loved ones and carers can also receive practical and emotional support.

Palliative care is about maintaining quality of life. The aim of palliative care is neither to hasten nor postpone death. Rather, the focus is on living as well as possible, for as long as possible.

Palliative care may include:

- Relief of pain and other symptoms
- · Medication management
- Food and nutrition advice and support
- Care and education to support better mobility and sleeping
- Planning for future medical treatment decisions and goals of care
- Resources such as equipment needed to aid care at home
- Assistance for families to come together to talk about sensitive issues
- Links to other services such as home help and financial support
- · Support for people to meet cultural obligations
- Support for emotional, social and spiritual concerns
- Counselling and grief support for the person with the illness, their family and carers
- · Referrals to respite care services
- Bereavement care to the family and carers once the person has died.

About National Palliative Care Week 2024

Up to four in five people who die could benefit from palliative care – or around 300 to 360 people every day in Australia. These numbers are increasing every year as our population ages and health needs become more complex; between 2020 and 2050 demand for palliative care is projected to double.

Unfortunately, many people who would benefit from palliative care miss out – especially but not only in rural and regional areas.

National Palliative Care Week (NPCW) 2024, held from Sunday 19 May to Saturday 25 May 2024, is Australia's largest annual initiative to raise awareness about palliative care, increase understanding of its services, and recognise the skill, dedication and 'heart' of the palliative care workforce and volunteers.

Our goal is to address the growing needs of the future so that all Australians who need it have access to palliative care.

Matters of life and death

Last year, the NPCW campaign centered around the poignant theme 'Matters of Life and Death', reaching over 2.13 million Australians. The campaign sparked conversations about death and dying, driving awareness and recognising the 'people at the heart of quality palliative care' – palliative care professionals, volunteers and carers, as well as people receiving palliative care, and their loved ones. The campaign drew its strength from the genuine stories of palliative care workers, whose personal experiences resonated deeply with audiences.

This year, PCA and our members have elevated our efforts, shedding light on the pressing need to educate and empower Australians about quality of life at the end of life. Expanding beyond the specialist palliative care workforce, this year's campaign encompasses a broader mix of palliative care professionals, volunteers, and individuals who have experienced palliative care firsthand

Death and dying remains a difficult subject for people to talk about and engage with and is often considered a taboo. This lack of engagement and awareness contributes to a widespread misunderstanding of what palliative care does and what it's all about.

During NPCW, our 'people at the heart of quality palliative care' will share what they know, address the most important questions about life and death and, in doing so, build a deeper understanding of palliative care, and encourage the community to take action.

The 2024 campaign videos will dive deeper into the 'matters of life and death' theme. They will explore the broad range of services and support that palliative care professionals and volunteers provide, as well as the personal experiences of someone receiving palliative care. These videos aim to help the public see palliative care as much more than death and dying but also something that inspires and fosters life.

What's in the toolkit and how to use it?

To help us reach as many Australians as possible, we need your help to spread the word during NPCW.

This toolkit provides individuals and organisations with information and campaign materials that can be used to promote NPCW 2024 in workplaces, on community billboards, in corner shops, media interviews, on social media – wherever your ideas take you.

In the next pages, we will be sharing the following resources:

- · Key messages for NPCW 2024
- Communication materials to promote and support NPCW 2024
- Tips on how to engage with your audiences
- · Key statistics

Key messages for NPCW 2024

- Palliative care is person and family-centred care provided to people of all ages with life-limiting illness, aimed at helping people live as well as possible, for as long as possible.
- Conversations about palliative care from the time of diagnosis of a life-limiting illness can ensure that you receive the holistic end-of-life care that you deserve.
- Palliative care can be delivered by General Practitioners, Registered Nurses, Nurse Practitioners, allied health professionals, aged care workers, volunteers and carers, as well as specialist palliative care services. They all play a critical role in delivering exceptional care and optimising quality of life.
- Palliative care should be available to people of any age living with a range of life-limiting illness
 dementia, heart and kidney disease, cancer, and many more.
- Palliative care can be accessed in a range of settings including at home, in hospital, in a hospice or in a residential aged care facility, so you can live the life you choose comfortably for as long as possible.
- Caring for people as they near the end of life is challenging. We are grateful for the dedication, passion, and skill of the palliative care workforce, carers, and volunteers.

Calls-to-Action for Social Media

- Palliative Care Australia and its members around the country have developed a road map of actions to increase access to palliative care for all Australians.
 Show your support and share it with your network
 - Palliative Care Australia Roadmap 2022-2027
 #MattersOfLifeAndDeath
- Death is confronting, which is why many of us find it hard to talk about. Consider sharing your story and experience as a way of opening conversations about death and dying and inspiring our community.
 - Share your story on social media, using #MattersOfLifeAndDeath.
- What does quality of life at the end of life look like to you? Start the conversation today. There are a range of tools available on the PCA website to support your thinking and planning, and prompt those conversations with your loved ones.
 - Visit palliativecare.org.au #MattersOfLifeAndDeath
- Caring for someone during the last chapter of life can be a challenging and emotional experience.
 Caring for yourself so that you can care for others is really important.
 - Explore the self-care and professional development ideas on the PCA website palliativecare.org.au #MattersOfLifeAndDeath

- If you work in health or care services and want to increase your skills and understanding of palliative care, explore the range of accessible education resources on the PCA website
 - Visit palliativecare.org.au #MattersOfLifeAndDeath
- Show your support and gratitude for those who deliver palliative care in your community, purchase and wear one of our orange hearts.
 - Visit palliativecare.org.au #MattersOfLifeAndDeath
- Show your support and care for those receiving palliative care in your community, purchase and wear one of our orange hearts.
 - Visit palliativecare.org.au #MattersOfLifeAndDeath
- Open conversations about matters of life and death in your community, purchase and wear one of our orange hearts.
 - Visit palliativecare.org.au #MattersOfLifeAndDeath

Promote and support NPCW 2024



Overview

Purchase and wear an orange heart

The 'orange heart' has been seen and used universally as a symbol for care and friendship. It is seen as being 'heart-warming and encouraging' and used as a symbol of 'always being there for me' – values that connect with palliative care.

It is now the new symbol of the palliative care sector and represents the warmth and spirit of palliative care, the connection that health professionals and volunteers share with patients and families and the close bonds that form during each person's unique palliative care journey.

The eight 'sparks' coming from the heart give it a sense of motion, a beating heart that points to the life palliative care supports; the sparks also represent Australia's eight states and territories and the role we all play in the delivery of palliative care.

Orange heart lapel pins can be purchased for \$5 from PCA and our members around Australia. Check the NPCW web page for online orders and local sales.

Funds raised are directed towards support, advocacy, and policy initiatives that help deliver palliative care to all Australians.

Digital resources

The NPCW 2024 digital resources can be used to communicate and spark conversations about palliative care. The resources include logos, posters, social media tiles and social media banners and media release template.

Download a posters and social media images

National Palliative Care Week 2024 <u>digital resources</u> are available for download.

We encourage you to share these resources to help us spread the word. You can choose to support the campaign in one or more of the following ways:

- Print posters to showcase in your workplace or share within your networks.
- Share NPCW images and banners on your organisation's social media platforms using the #MattersOfLifeAndDeath hashtag.



Engage on social media

- Please follow Palliative Care Australia and our member organisations on Facebook, X and LinkedIn to join the conversation.
- Tag our social media channels while sharing your content.
- Use our campaign hashtag #MattersOfLifeAndDeath on your posts so we can re-share your message.
- While posting your content, we encourage you to prompt your users to visit <u>palliativecare.org.au</u>
- Refer to 'Key Messages' and 'Calls to Action' above for content inspiration.

Include a NPCW 2024 logo on your digital channels

You can feature the NPCW 2024 logo on your website, Facebook page, LinkedIn profile, X and Instagram account to show your support for palliative care.

The logo is available to download via our digital resources.

Media release template

You can reach out to your local media with our media release template available to download via our digital resources.

Tell us your palliative care story

Are you a palliative care worker or volunteer or have experienced or know someone who has or is currently experiencing palliative care? We'd love to hear your story.

You can share your story via your social media channels by using the hashtag #MattersOfLifeAndDeath.

Alternatively, you can tell us your story by emailing us at pca@palliativecare.org.au and we will help you.

Share photos and stories from your event

Are you hosting a NPCW 2024 event? You can share photos and stories from your event on social media by using the hashtag #MattersOfLifeAndDeath. We will reshare your event through our channels.

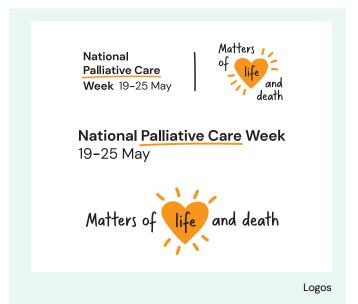
Share with your network

We encourage you to share this toolkit with any individual or organisation you think would be a good advocate during NPCW 2024.

Include a NPCW 2024 logo on your digital channels

You can feature the NPCW 2024 logo on your website, Facebook page, LinkedIn profile, and X and Instagram account to show your support for palliative care.

The logo is available to download via our digital resources.







Social media tiles



X cover photo



Facebook cover photo



LinkedIn cover photo

How to engage with your audiences



Tips for contacting your local media

Prepare a media release using the media release template available to download on our website. Feel free to include additional information about your organisation and event. PCA would love to receive a copy of the media release so please send it to pca@palliativecare.org.au

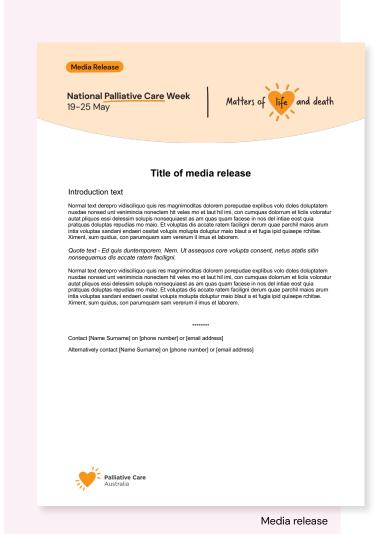
Most media outlets have their contact details on their website and can also be reached via social media. You can either call or email the media release to the journalist to pitch your idea or event for potential coverage.

Contact your local radio station and ask for a slot to speak about your story or event.

Invite the journalist to attend your event. You can also provide interview and photo opportunities with key stakeholders from your organisation. Think about who your spokesperson/s is beforehand and have them ready.

Make sure you take good images of the event, or screen captures of your virtual event to share it with your local media post-event.

Personal stories carry so much weight and interest for local media and their audiences. Do you or someone in your network have an experience to share?



Death and Dying in Australia – The Facts



- Over half (53%) of all deaths in Australia would benefit from palliative care (Sleeman et al). This is made up of people with life-limiting illnesses like dementia, heart disease, cancer and more. Other research (Murtagh 2014) puts the number as high as 82%, which reflects our aging population and growing levels of chronic disease.
- Demand for palliative care will increase by 50% between now and 2035, and double by 2050 as Australia's population ages and the level of chronic disease in our community grows (KPMG).
- The number of people dying year-on-year in Australia is increasing.
- 190,939 people died in 2022 the latest numbers available. Over two-thirds (67%) of people who died in 2022 were aged 75 or over (ABS).
- Each day in Australia up to 360 people die who could benefit from palliative care. (ABS and Murtagh et al).
- The number of deaths is projected to increase from 190,939 in 2022 to between 378,200 and 402,800 annually in the coming decades (ABS).
- More people in Australia are living longer (ABS). This
 is a result of better medical treatment and care.
- Over the past decade, life expectancy increased 1.3 years for men and 1.0 years for women (ABS, 2020-22). Life expectancy for men was 81.2 years in 2020-22. Life expectancy for women was 85.3 years in 2020-22 (ABS).
- The life expectancy of Australians is the third highest in the world (ABS).
- Life-limiting illnesses are the leading cause of death in Australia (ABS). The 5 leading causes of death in Australia in 2022:
 - 1. Heart disease
 - 2. Dementia
 - 3.COVID-19
 - 4. Stroke
 - 5.Lung cancer

- Aboriginal and Torres Strait Islander people are more likely than non-Indigenous people to live with and die of life-limiting illnesses (AIHW).
- Life-limiting illnesses are the leading causes of death for Aboriginal and Torres Strait Islander people (ABS). The 5 leading causes of death for Indigenous Australians:
 - 1. Heart disease
 - 2. Diabetes
 - 3. Chronic obstructive pulmonary disease (COPD)
 - 4. Lung cancer
 - 5.Suicide
- Around 70% of people, when asked, say they would prefer to die at home. (Swerissen and Duckett).
 Desipte this, the majority of deaths in Australia occur in hospital or other medical settings (ABS).
- Between 2015–16 and 2021–22, palliative care related hospitalisations grew by 29% (73,600 to 94,800) close to triple the rate for all other hospitalisations. (AIHW)
- In June 2022, more than 180,500 people lived in permanent residential aged care. Most had complex health needs (AIHW).
- Three of every 10 people die in residential aged care.
 Half of those aged 85 and over die in residential aged care (AIHW).
- 96% of Australians believe it is important that aged care services are able to provide palliative care to their residents (PCA).
- The Royal Commission into Aged Care Quality and Safety made 12 recommendations pointing to the need for palliative care to be embedded within aged care.
- Palliative care is delivered to people of all ages including infants, children, teenagers and young adults.
- Around 29,000 children and young people are currently living with a life-limiting condition in Australia (ABS).

- Less than half (46%) of all children who died in 2021 with a life-limiting condition received specialist paediatric palliative care (AIHW).
- Children from regional and remote areas tend to not live as long as, and die at a younger age than, children from major cities (AIHW).
- People living in major cities are 3.4 times more likely to receive specialist palliative care than those in rural and remote areas, in 2021-22. (AIHW)

What needs to be done to improve access to quality palliative care?

Palliative Care Australia Roadmap 2022-2027

PCA and our members have developed a Roadmap for meeting this burgeoning need for palliative care in Australia.

The Roadmap addresses key areas which need to be prioritised:

- Greater investment in dedicated palliative care services across Australia including rural and remote areas.
- Supporting and growing the palliative care workforce – this includes upskilling those working in aged care and primary health.
- Making palliative care core business in aged care a key finding of the Royal Commission into Aged Care Quality and Safety.
- Providing more home-based supports so that people can be cared for and die in their place of choice.
- Investing in palliative care awareness campaigns to raise community awareness about death, dying and palliative care.

Read and download the full Roadmap HERE.

Thank you for helping Palliative Care Australia raise awareness, and spark conversations.

We also appreciate your support in recognising and celebrating the incredible dedication of the 'people at the heart of quality palliative care' across Australia.

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