



PalliativeCare
AUSTRALIA

Palliative Care Australia Roadmap 2022-2027

Investing to secure high-quality palliative care for all Australians who need it



Palliative Care: it's everyone's right!



Acknowledgement of Country

Palliative Care Australia (PCA) is located in Canberra on the land of the Ngunnawal People. PCA wishes to acknowledge the traditional owners of this land, the Ngunnawal People and their Elders past and present. We acknowledge and respect their continuing culture and the contribution they make to the life of this city and this region.



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Executive Summary

To see a palliative care system across Australia that provides access to quality palliative care will require governments and other funders to see its worth and advocate for increased investment and policy support.

Palliative Care Australia (PCA) offers the following Roadmap to guide them in the direction that Australia needs to take from now till 2027 to ensure high-quality palliative care for all who need it, where and when they need it. 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 the specialist palliative care workforce and the workforce in primary care.
- Making palliative care core business in aged care – a key finding of the Royal Commission into Aged Care Quality and Safety.
- Augmenting palliative care data and research.
- Providing more support to carers so they can care for their loved ones in the place of choice.
- Fully funding the Paediatric Palliative Care Action Plan.
- Investing in palliative care awareness campaigns to raise community awareness about death, dying and palliative care.

The demand for palliative care is increasing, with the estimated demand in Australia expected to increase by 50% between now and 2035, and double by 2050¹.

The population is growing and ageing, and many people will be diagnosed with chronic illnesses, which will increase the need and demand for palliative care in Australia.

As the peak body for palliative care in this country, PCA has developed a Roadmap for meeting this burgeoning need for palliative care in Australia.

While there are excellent palliative care services spread throughout Australia, there has been chronic underinvestment across parts of the health system to meet the needs of the growing number of people who are diagnosed with a life-limiting illness each year.

The COVID-19 pandemic has presented many learnings for the health sector. Palliative care has been at the forefront of the pandemic, offering care to dying patients and supporting health professionals in hospitals and the community to meet the needs of dying patients and their families. Palliative care provided in community settings has been pivotal in reducing the number of hospital admissions from palliative care patients so that hospital beds could be freed to meet the demand from COVID-19 patients.

Voluntary Assisted Dying has or is being legislated in jurisdictions across Australia. It is particularly concerning that many people consider that the option of voluntary assisted dying provides dignity and choice when it comes to end-of-life care and may not consider evidence-based palliative care as a choice for providing quality of life at the end of life. Palliative care offers dignity and choice – but it needs to be resourced and prioritised to ensure this.

All Australians deserve to be cared for appropriately when they have been diagnosed with a life-limiting illness. However, in Australia, only one in six public acute hospitals has a specialist palliative care inpatient unit², and of those that do, many are cutting back on the amount of time people can stay or the number of beds dedicated to palliative care.

The majority of people in rural and regional Australia cannot access palliative care unless they travel long distances (often hundreds of kilometres) to access a service. In residential aged care, where many people will spend their last months and years of life, the capacity for services to provide appropriate care at the end of life is limited by the skills and availability of the workforce and the resources available to provide the necessary supports and services.

Unpaid carers, usually a person's loved ones, provide untold hours of care and support, and they need access to expedited support services and respite options.

Australia needs to invest in developing and increasing the palliative care workforce spread across the country. We need more palliative medicine physicians and more palliative care nurses and the involvement of more allied health workers. These professions are critical to the specialist palliative care workforce. The health and aged care workforce based in primary care, allied health, aged care and areas such as pharmacy also need to be supported and upskilled.

These health professionals provide care to people with a life-limiting illness day in day out within our health and aged care system. They also need to be supported by a strong specialist palliative care workforce to refer people when needs become more complex.

Palliative care provides quality of life for people and their loved ones and aids in reducing the need for access to mental health services and acute and emergency departments. In addition, palliative care benefits the health system and provides a known return on investment as it takes pressure off the health system and is a cost-effective way to deliver care.

The time to take action is **NOW.**

We know we can achieve better social and health outcomes while also reducing the almost \$8 billion spent on death each year.

There are many medical interventions that result in positive health and social outcomes. Palliative Care is particularly unique in that as well as improving the quality of life for those with a life-limiting illness, it also provides a positive return on investment.

KPMG estimates that a **\$1** investment in:

Integrated community and home-based palliative care services can return between



Palliative care in hospital delivers a return between



Palliative care Innovative models in residential aged care delivers a return between



Introduction

The PCA Roadmap sets out the investment and initiatives needed in palliative care over the next five years to ensure that Australians have access to high-quality palliative care when they need it and where they need it.

WHAT IS PALLIATIVE CARE?

PCA subscribes to the World Health Organization (WHO) definition of palliative care:

Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.³



People living with a life-limiting illness deserve high-quality care. They and their families, carers and loved ones want to know that high-quality palliative care will be available when and where people need it.

Investment in palliative care means people can live well until their death, with optimal management of symptoms, support and care in the place of their choice.

Investment in palliative care also makes economic sense. People living with a life-limiting illness who receive palliative care, compared with those who do not, have fewer hospitalisations, shorter hospital stays, reduced use of Intensive Care Units and fewer visits to Emergency Departments (EDs).⁴

PALLIATIVE CARE AUSTRALIA

Palliative Care Australia represents all those who work towards high-quality palliative care for all Australians who need it. Working closely with consumers, our Member Organisations and the palliative care workforce, we aim to improve access to, and promote the need for, palliative care.

NATIONAL PALLIATIVE CARE STRATEGY

PCA welcomed the release of the 2018 National Palliative Care Strategy (The Strategy). The Strategy provides an overarching vision for palliative care in Australia: that people affected by life-limiting illnesses get the care they need to live well. The Strategy highlights the need to plan for the increasing demand for palliative care as the Australian population ages and people with chronic disease and disabilities live longer.

Investment at national, state and territory levels will be required to ensure that the systems and people are available to provide quality palliative care when and where it is needed.⁵

The development of the Roadmap has been driven by the vision, principles and goals of the Strategy, which with current levels of investment **are not being realised**.

PCA will review this Roadmap every 12 months and report on progress on each of the activities on the following pages.



PALLIATIVE CARE OFFERS



Control

Palliative care is about finding out from the person what they want and do not want as they come close to the end of their life and being guided by those directions.



Dignity

Palliative care is holistic care that puts the person's needs at the centre of the care provided with their goals and wishes respected and acted upon.



Choice

Palliative care helps a person with a life-limiting illness manage their affairs so they can make choices and decisions about treatment, care options and how they want to spend their time.



Guidance on their journey

Palliative care professionals guide a person with a life-limiting illness so that they do not feel alone and have support in navigating their illness journey.



Quality of life

Palliative care is about living as well as possible for as long as possible. Palliative care professionals provide care for body, mind and spirit. Palliative care treats pain and symptoms like fatigue and breathlessness; when these are controlled, a person has a much better quality of life.



Support for family and loved ones

Palliative care sees a person with life-limiting illness within the broader context of their family and support network. Palliative care services can include support for carers through respite and home care options as well as providing grief and bereavement support.

PCA Roadmap 2022–2027



PCA Roadmap 2022–2027

Roadmap 2022–2027

Palliative Care Australia

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INVESTMENT

SOLUTION

Increased Australian Government investment in palliative care service delivery, workforce development, research and data

ISSUES TO ADDRESS

Many Australians are unable to access high-quality palliative care where and when they need it. This is especially difficult in rural and remote Australia and for people from diverse needs groups

Carers are struggling to provide care to people with life-limiting illnesses and access respite and other carer services

There are inadequate levels of skilled and trained staff to deliver palliative care across the health and aged care sectors

There is inadequate data and research about palliative care to build a strong evidence base and assist in planning and identifying unmet and emerging need

Australians are not talking about death and dying and have a limited understanding of what palliative care can deliver

Young Australians and their families are struggling to access appropriate paediatric palliative care

INVESTMENT	IMMEDIATE 2022-2024	SHORT TO MEDIUM TERM 2025-2027
	Service Delivery	Service Delivery
	<p>» Immediately increase funding for direct delivery of palliative care in home-based, hospital and residential aged care settings with a minimum increase in investment of:</p> <ul style="list-style-type: none"> - \$240 million per year to dramatically increase the provision of palliative care in the home and community. Such an investment would respond to the increasing demand for being cared for and dying at home with funding to provide integrated home and community-based palliative care support and ensure quality of life and a dignified death. It would also allow for more than 35,000 deaths to occur at home and be cost neutral due to 28,500 fewer ED visits and over 200,000 fewer hospital bed days⁶. - \$87.5 million per year to increase the number of registered palliative care nurses in residential aged care facilities. This would fund an additional 1,100 registered palliative care nurses to provide palliative care services to residents. This is an initial investment to be increased in the short to medium term. - \$50 million per year to provide specialist palliative care services for residents with complex needs in residential aged care services. This would provide access to specialist palliative care staff to complete 'needs rounds' and subsequent provision of palliative care services for approximately half of all residents of aged care facilities across Australia with complex needs. This is an initial investment to be increased in the short to medium term. - \$50 million per year to increase the number of specialist palliative care beds and integrated palliative care teams in hospitals, supporting an extra 6,500 palliative care episodes each year. <p>Note: Figures as per the KPMG report⁷</p> <p>» National Health Agreement on Palliative Care to be signed by the Australian Government and all state and territory governments, with performance indicators and incentive payments built in.</p> <p>» Increase in investment to support integrated care across national and state/territory health systems.</p> <p>» Funding models for acute care updated to include resources to deliver bereavement care to families and loved ones after a person's death.</p> <p>» Increase in investment to support the development of new integrated models of care which ensure seamless transitions of care between specialist palliative care and primary and other health specialist care.</p> <p>» Increase in Medicare Benefits Scheme (MBS) rebates for Palliative Care Nurse Practitioners to support the delivery of palliative care services, especially in aged care, rural and remote areas and for those working with Aboriginal and Torres Strait Islander Communities.</p>	<p>Increase the funding per year for residential aged care to:</p> <ul style="list-style-type: none"> » \$175 million per year to provide a minimum of one registered palliative care nurse per residential aged care facility. This would fund an additional 2,200 registered palliative care nurses to provide palliative care services to the 200,000 residents of residential aged care facilities (RACFs) who need it. » \$100 million per year to provide specialist palliative care services for residents with complex needs in residential aged care services. This would provide access to specialist palliative care staff to complete 'needs rounds', and subsequent provision of palliative care services, for all of the 100,000 residents of aged care facilities across Australia with complex needs. » Palliative care funding agreements in place to secure funding for palliative care in all public hospitals across all cities and regions. » All jurisdictions funded to provide 24-hour palliative care advice and support. » Respite centres that support people receiving palliative care and their carers in all capital and regional cities. » Integrated models of care between specialist palliative care and primary and other health specialist care are operating across Australia.

INVESTMENT (continued)

IMMEDIATE 2022-2024		SHORT TO MEDIUM TERM 2025-2027	
INVESTMENT	Workforce		
	<ul style="list-style-type: none"> » Immediate development of a National Palliative Care Workforce Strategy that includes strategies for increasing the workforce and succession planning. » Fund modelling research to determine the level of palliative care workforce required in all settings across Australia recognising that different models may be required across metropolitan, rural and remote locations and to support diverse needs populations and paediatric palliative care. » Training for primary care and the specialist (non-palliative care) providers to understand and adhere to the Addendum for all health professionals to the National Palliative Care Standards. » Training for General Practitioners to better understand palliative care and support patients through their palliative care journey. 	<ul style="list-style-type: none"> » Increase in the palliative care workforce in line with modelling including, at a minimum: <ul style="list-style-type: none"> - Two full-time equivalent specialist palliative medicine physicians per 100,000 population. - A substantial increase in palliative care nurses and palliative care nurse practitioners in a range of locations across the health and aged care systems. - Adequate staffing to adequately cover paediatric palliative care, rural and remote locations and address the needs of diverse populations. - Modelling for specialist palliative care medicine physicians should be regularly updated to reflect the increasing size and diversity of the Australian population. Modelling for palliative care nurses and palliative care nurse practitioners should be commenced. » Establishment of a Palliative Care postgraduate scholarship scheme to provide funding for successful medical, nursing and allied health candidates to undertake postgraduate training in palliative care. » Establishment of a mentoring program to provide support to the emerging palliative care workforce. » Development of resources to support the well-being of the palliative care workforce, including expansion of the PCA <i>Self-Care Matters</i> resources. » All undergraduate training in medicine, nursing and allied health includes content on dying, grief and bereavement and palliative care. 	
	Research and Data		
	<ul style="list-style-type: none"> » Australian Government commits a minimum of \$10 million per year dedicated to palliative care and end of life research. » Immediately establish a Palliative Care National Minimum Data Set for health, aged care (residential and home care) and paediatrics. » Immediately increase funding for the Australian Institute of Health and Welfare (AIHW) and state and territory governments to support increased data collection in palliative care and aged care, including the development of data sets. » Improved data collection on the specialist palliative care nursing workforce. 		

IMMEDIATE 2022-2024		SHORT TO MEDIUM TERM 2025-2027	
INVESTMENT	Communication Campaigns		
	<ul style="list-style-type: none">» Immediately increase funding to improve community awareness around death, dying and palliative care, including:<ul style="list-style-type: none">- Funding for Palliative Care Australia to continue the Palliative Care: <i>Its More than you Think</i> Campaign extending radio and TV advertisements across Australia, including all capital cities.- Education on understanding what palliative care can be and what should happen when accessing palliative care.» Communication campaign for health providers to better promote the use of the palliative care section of the Pharmaceutical Benefits Scheme (PBS).		
	Carer Support		
	<ul style="list-style-type: none">» A separate expedited assessment process at Services Australia for carers of people with life-limiting or terminal illness that allows carers to receive payments quickly.» Increased investment in respite services for people receiving palliative care and carers, including planned and emergency respite (paediatric and adult).» Improved access to timely in-home support including services, equipment, information, education and resources.» Early identification of carers' emotional and physical health needs, including during bereavement.		
	Paediatric		
	<ul style="list-style-type: none">» A fully funded paediatric palliative care peak body.» A fully funded Paediatric palliative care action plan.		



AGED CARE

SOLUTION

Making palliative care core business in aged care

ISSUES TO ADDRESS

Many Australians are dying in aged care without adequate access to palliative care

People receiving palliative care cannot access aged care and NDIS services in a timely manner

Palliative care is not core business in aged care and approved providers are not adequately funded to deliver it

The aged care workforce is not adequately skilled and trained to meet the palliative care needs of care recipients

		IMMEDIATE 2022-2024	SHORT TO MEDIUM TERM 2025-2027
AGED CARE	Regulatory Framework		
		<ul style="list-style-type: none"> » Immediately establish a new Aged Care Act that incorporates palliative care. » Aged Care Quality Standards reviewed and updated, including standards around the delivery of palliative care. 	<ul style="list-style-type: none"> » All home care services that provide palliative and end-of-life care are accredited by the Australian Government.
	Service Delivery		
		<ul style="list-style-type: none"> » All aged care providers delivering palliative care as per the updated Standards and Act. » 2023 – the new at-home care program includes a palliative care category. » Australian Government to work with state and territory Governments to introduce Local Hospital Network-led multidisciplinary outreach services, which include palliative care specialists and outreach services. » Older Persons Mental Health Services funded to provide outreach services in residential and home aged care. » Immediate investment in services to provide palliative care for people with dementia. 	<ul style="list-style-type: none"> » The National Health Reform Agreement updated to include: <ul style="list-style-type: none"> - An explicit statement of the respective roles and responsibilities of approved aged care providers and State and Territory health care providers to deliver health care to people receiving aged care; and - Explicit commitments by state and territory governments to provide access by people receiving aged care to state and territory government-based health services (including palliative care services). » Aged care providers have the resources to provide appropriate palliative care for people with dementia.
	Assessment and Referral		
		<ul style="list-style-type: none"> » People with a terminal diagnosis of less than three months are eligible for immediate referral to services by My Aged Care. » People with a terminal diagnosis of less than six months are given the highest priority level for an assessment. » People with a terminal diagnosis of less than six months are given the highest priority level when entering the National Prioritisation System. 	

AGED CARE *(continued)*

IMMEDIATE 2022-2024		SHORT TO MEDIUM TERM 2025-2027	
AGED CARE	Training		
	<ul style="list-style-type: none"> » Updated Certificate III in Individual Support includes compulsory palliative care and dementia units for those undertaking the Aged Care specialisation. » Updated Certificate IV in Ageing includes compulsory palliative care and dementia units » Funding for additional training places in Certificate III and Certificate IV courses and additional staffing hours so existing employees can attend training. » All aged care staff have undertaken palliative care and dementia training. 	<ul style="list-style-type: none"> » All staff in aged care have a minimum Certificate III qualification. » Funding to create an aged care career pathway including scholarships for staff to upgrade qualifications including: <ul style="list-style-type: none"> - Personal care workers upgrading to Certificate IV and Diploma of Nursing Qualifications. - Enrolled nurses upgrading to Registered Nurse. - Registered Nurses upgrading to Nurse Practitioner. » Establishment of a network of Centres for Excellence to deliver palliative care and dementia units to the aged care workforce. 	
	Workforce		
	<ul style="list-style-type: none"> » Aged Care workforce increased to meet the new requirement for 200 minutes of care time per resident per day, including 40 minutes by a registered nurse. This should include minimum staffing available 24 hours a day to make clinical decisions and give medicines when people need them. 		
	Aged Care Pricing		
	<ul style="list-style-type: none"> » Department of Health to set a AN-ACC pricing schedule that fully funds providers to deliver palliative care. » October 2022 – AN-ACC pricing schedule provides funding for an average of 200 minutes of care time per resident per day, including 40 minutes by a registered nurse to support the amount of direct care time needed for the delivery of palliative care. » 2023 – The Independent Hospital and Aged Care Pricing Authority (IHACPA) to continue the AN-ACC pricing schedule, ensuring a link with the newly updated standards. » 2023 – IHACPA sets a price that fully funds the care at home palliative care category. 		

IMMEDIATE 2022-2024		SHORT TO MEDIUM TERM 2025-2027
AGED CARE	Data	
	» Include palliative care data in an aged care National Minimum Data Set.	
	NDIS	
	» Establishment of a specialised palliative pathway for paediatrics and adults to allow for expedited access requests, approvals for access and planning processes.	





MEDICINES

SOLUTION

Increased investment in palliative care medicines schedule, training and communications

ISSUES TO ADDRESS

People receiving palliative care do not have access to palliative care medicine where and when they need them

The health and aged care workforce are not adequately trained and supported to provide medicines to people receiving palliative care

IMMEDIATE 2022-2024		SHORT TO MEDIUM TERM 2025-2027	
MEDICINES	Pharmaceutical Benefits Schedule (PBS)		
	» Instigate a defined timeframe for regular review of the palliative care medicines schedule of the PBS.		» Three yearly schedule reviews of the palliative care medicines schedule of the PBS.
	Workforce		
	» Funding for real-time prescription monitoring to support the workforce in evidence-based use of opioids (as currently done under the Safe Scripts program used in Victoria).		
	» Specialised training in evidence-based use of opioids for the palliative care workforce aligned with the updated evidence-based cancer pain and palliative care guidelines.		
	» Residential aged care workforce receive training in medication management and reviews, particularly registered nurses.		
Communication Campaigns			
» Communications campaign to educate primary care health professionals about appropriate prescribing of opioids for people receiving palliative care.			



GRIEF AND BEREAVEMENT

SOLUTION

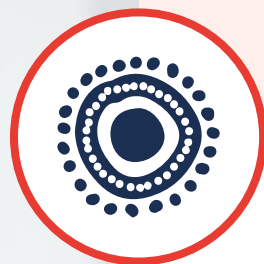
Investment in grief and bereavement standards, research and services

ISSUES TO ADDRESS

Many Australians, including carers and healthcare and aged care workers, struggle to access appropriate grief and bereavement services

Healthcare and aged care services are not required to or appropriately resourced to provide grief and bereavement services

GRIEF AND BEREAVEMENT	IMMEDIATE 2022-2024	SHORT TO MEDIUM TERM 2025-2027
	<ul style="list-style-type: none"> » Immediately fund the incorporation of death and dying principles and practices in the National Disaster Mental Health and Wellbeing Framework and fund specific palliative care grief and bereavement services. » Develop national standards for bereavement service provision in Australia based on best practice of optimal bereavement interventions. » Investing in research about the mental health, grief and bereavement impacts, including the impact of COVID-19. » Incorporating access to grief and bereavement services in the Aged Care Quality Standards. » Funding models for acute care updated to include resources to deliver bereavement care to families and loved ones after a person's death. 	<ul style="list-style-type: none"> » Implement national standards for bereavement service provision in health and aged care services.



ABORIGINAL AND TORRES STRAIT ISLANDER PALLIATIVE CARE

SOLUTION

Investment in the development and delivery of culturally appropriate care models and aged care pathways for Aboriginal and Torres Strait Islander people

ISSUES TO ADDRESS

Many Aboriginal and Torres Strait Islander people struggle to access culturally appropriate and trauma-informed palliative care, where and when they need it

Many Aboriginal and Torres Strait Islander people struggle to access culturally appropriate aged care and have their care needs assessed and understood

Many health and aged care services delivering palliative care do not have appropriate training and understanding of the needs of Aboriginal and Torres Strait Islander people

IMMEDIATE 2022-2024

- » Immediately fund the development of a National Palliative Care Action Plan for Aboriginal and Torres Strait Islander People.
- » Development of culturally appropriate care models to support Aboriginal and Torres Strait Islander people living with a life-limiting disease.
- » Development and introduction of cultural awareness training for all palliative care providers.
- » Development of further resources to support advance care planning for Aboriginal and Torres Strait Islander people.
- » Training and career pathways for the Aboriginal and Torres Strait Islander palliative care workforce.

SHORT TO MEDIUM TERM 2025-2027

- » Implementation of culturally appropriate care models to support Aboriginal and Torres Strait Islander people living with a life-limiting disease. This model should also support people to die in their place of choice, including support to return to Country.
- » Mandatory requirement for palliative care providers to undertake cultural awareness training.
- » Funding and resources for palliative care services to provide trauma-informed care to members of the Stolen Generation.

Aged Care

- » Establishment of an Aboriginal and Torres Strait Islander Aged Care Commissioner.
- » Development of a national Aboriginal and Torres Strait Islander Aged Care Workforce plan.
- » Establishment of an aged care pathway and supports Aboriginal and Torres Strait Islander people to access and navigate the aged care system.
- » Development of culturally appropriate integrated models of care for older Aboriginal and Torres Strait Islander people.
- » Development of culturally appropriate assessment tools for Aboriginal and Torres Strait Islander people.
- » Aboriginal community-controlled organisations assisted to expand into aged care.
- » Aboriginal and Torres Strait Islander specific assessment organisations providing assessment for entry to aged care.
- » Aboriginal and Torres Strait Islander providers allowed to flexibly pool aged care funds across home care, residential care and respite care.
- » Grants provided to fund innovative, and purpose-built construction of aged care facilities, including maintenance and upgrades, staff housing and technology upgrades.
- » Establishment of a network of Aboriginal and Torres Strait Islander system navigators to assist Aboriginal and Torres Strait Islander people with assessment and entry into aged care
- » Research undertaken to determine aged care service gaps for Aboriginal and Torres Strait Islander people.

- » All Aboriginal and Torres Strait Islander people able to access and navigate the aged care system via the Aboriginal and Torres Strait Islander aged care pathway.
- » All Aboriginal and Torres Strait Islander people able to be assessed by Aboriginal and Torres Strait Islander specific assessment organisations.
- » All Aboriginal and Torres Strait Islander people able to access an Aboriginal and Torres Strait Islander system navigator.
- » Aged care service gaps for Aboriginal and Torres Strait Islander people are addressed and funded.

Key Concepts and Background Information

OVERARCHING PRINCIPLES

The PCA Federal Election Roadmap is guided by the following overarching principles:

- Palliative care helps people live their life as fully and as comfortably as possible when living with a life-limiting or terminal illness, and provides support to carers and loved ones

- Palliative care is everyone's business

- Palliative care can help people to plan and make decisions

- Palliative care allows people to feel more control over what is happening to them

- Palliative care can be for people of all ages and for people with all forms of life-limiting illness

- The benefits of palliative care are increased by identification for referral and access to service

PALLIATIVE CARE NEED

Despite the lack of high-quality data in palliative care, there is still strong evidence that palliative care in Australia is currently not meeting demand. Data collected by the Australian Palliative Care Outcomes Collaboration (PCOC) shows that:

- » A substantial proportion of patients that are referred to specialist palliative care services are referred with moderate-severe distress and symptom severity. This suggests that a proportion of patients and families are referred late to specialist palliative care services in Australia⁸.

- » Approximately 95% of specialist palliative care services are registered with PCOC. At the total population level, PCOC reported on 14% of all deaths in Australia in 2018. This suggests that a large proportion of residents in Australia that may benefit from palliative care are missing out on receiving it⁹.

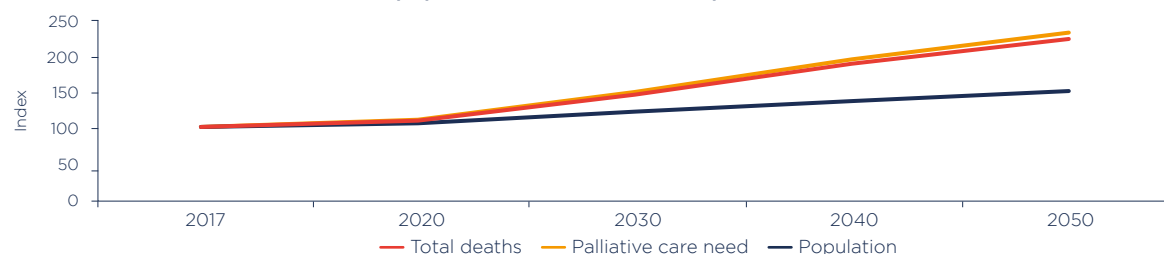
- » Between 2017-2020, the proportion of patients and families referred to specialist palliative care by general practitioners has remained constant. This suggests that more needs to be done to increase referrals from primary care to specialist palliative care¹⁰.

- » Although the proportion of those that access specialist palliative care when diagnosed with a non-malignant disease has increased over time, access to specialist palliative care for those with a non-malignant disease remains an issue¹¹.

Further data analysis has shown that:

- » Demand for palliative care is expected to increase by 50% between now and 2035, and double by 2050.

Growth in the estimated population, total deaths, and palliative care need (2017-2050)





Home and Community Care

- » There is a 'postcode lottery' in the provision of palliative care services in the home and community.
- » Just 2,240 Australians received an MBS-funded palliative care home visit during 2019/20, about a third of deaths in-home care¹². There is a stark decrease in access to MBS-funded palliative care services per 100,000 population outside major cities, with outer regional areas accessing about half the level of MBS-funded services as major cities; and remote areas accessing just a quarter of the level of services¹³.
- » Due to COVID-19, demand for palliative care services in the home and community increased dramatically. Palliative Care South East, a service provider in metropolitan Melbourne, noted that demand increased by 61% since the pandemic began, which has not attracted additional funding¹⁴.



Residential Aged Care

- » There is a substantial unmet need for palliative care in RACFs. Over 53% of residents have high complex health care needs¹⁵, and there are over 53,000 deaths in RACFs each year¹⁶. Yet in 2018/19 under the current Aged Care Funding Instrument, just 3,178 residents were appraised as needing palliative care, accounting for less than 6% of deaths in RACFs¹⁷.
- » The new AN-ACC funding model has specific palliative care provisions, but the impact on increasing the provision of palliative care, reducing the unmet need and improving resident outcomes is yet to be determined.



Hospitals

- » Only one in six public acute hospitals in Australia has a specialist palliative care inpatient unit.¹⁸
- » There is a large variation in access to palliative care in hospitals – in Victoria, there are 12.2 palliative care public hospital hospitalisations per 10,000 population; in NSW, the rate is 21.1 per 10,000 population¹⁹.



Workforce

- » While demand for palliative care has been growing at over 3% per annum over the last five years²⁰, the number of palliative care nurses have grown at 2% per annum²¹, exacerbating unmet need.
- » Research has found high numbers of GPs are involved in the palliative management of a patient (82%). However, up to a third (31%) of these GPs lack confidence in providing this care because of patient complexity, inadequate training and insufficient resources²².



INVESTMENT IN PALLIATIVE CARE

In 2020, PCA commissioned KPMG to undertake an economic study into the value of palliative care. *Investing to Save: The Economics of Increased Investment in Palliative Care in Australia* (KPMG Report) presents the clear economic case for increased investment in palliative care. The KPMG Report highlights opportunities for governments to generate significant returns on their investments and deliver lower end-of-life costs in palliative care, while at the same time achieving positive health and social outcomes for people with life-limiting conditions. The report focuses on targeted practical and evidence-based interventions.

PCA and KPMG recommend additional annual investment to fully fund palliative care:

- » \$240 million per year to increase funding and timely access to home and community-based palliative care services. Such an investment would respond to the increasing demand for dying at home with funding to provide integrated home and community-based palliative care support and ensure a planned and dignified death. It would also allow for more than 35,000 more deaths to occur at home and be cost neutral due to fewer ED visits and hospital bed days.
- » \$175 million per year to provide a minimum of one registered palliative care nurse per residential aged care facility. This would fund an additional 2,200 registered palliative care nurses to provide palliative care services to all of the almost 200,000 residents of RACFs. Due to the extensive time required to train and recruit this additional workforce this funding can be ramped up over five years.

» \$100 million per year to provide specialist palliative care services for residents with complex needs in residential aged care services. This would provide access to specialist palliative care staff to complete 'needs rounds' and subsequent provision of palliative care services, for all of the 100,000 residents of aged care facilities across Australia with complex needs. Due to the extensive time required to train and recruit this additional workforce this funding can be ramped up over five years.

» Additional \$50 million per year to increase the number of specialist palliative care beds and integrated palliative care teams in hospitals, supporting an extra 6,500 palliative care episodes each year²³.

The report shows that we can achieve better social and moral outcomes while also reducing the almost \$8 billion spent on death in Australia each year.

"Increasing the provision of palliative care services not only improves health and social outcomes for people experiencing life-limiting conditions, but also helps to lower end-of-life costs to Government."

Dr Chris Schilling

KPMG Senior Health Economist and report author



AGED CARE

Palliative Care in Aged Care

Palliative care in aged care is a human rights issue. In October 2021, the Human Rights Council of the United Nations General assembly adopted a resolution on the human rights of older persons that includes references to palliative care, including calling on member states to:

- » Prohibit ‘all forms of discrimination against older persons and to adopt and implement non-discriminatory policies, national strategies, action plans, legislation and regulations, and to promote and ensure the full realization of all human rights and fundamental freedoms for older persons including...long-term support and palliative care services’; and
- » ‘Take measures to combat ageism and eliminate age discrimination, and to protect the human rights of older persons in... long-term support and palliative care services’.

PCA has, together with the palliative care and aged care sector more broadly, advocated strongly for many years that palliative care must be considered core business in aged care. As Australia’s population ages and the number of people using aged care services increases, the demand for palliative care in community and residential aged care is also increasing. Currently, 36% of all deaths in Australia occur in residential aged care²⁴, and increasing numbers of people are receiving aged care services in their homes.

Currently, palliative care in aged care is not supported by the aged care regulatory framework (Aged Care Act and Aged Care Quality Standards), aged care funding models or training and support systems for staff. Aged care providers and their staff must be supported by appropriate systems, funding and training to provide quality palliative care.

The Royal Commission into Aged Care Quality and Safety’s (Royal Commission) final report acknowledges that evidence heard during the life of the Royal Commission shows that too few people receive evidence-based end-of-life and palliative care, and instead experience unnecessary pain or indignity in their final days, weeks and months. The Royal Commission recognised the significant role palliative care has in aged care and the need for it to be core business:

“Palliative and end-of-life care, like dementia care, should be considered core business for aged care providers. People at the end of their lives should be treated with care and respect. Their pain must be minimised, their dignity maintained, and their wishes respected. Their families should be supported and informed.”²⁵

PCA welcomed the recommendations made by the Royal Commission (and accepted by the Government) to support palliative care in aged care. This includes:

- » The introduction of a new Aged Care Act that specifies the rights of people seeking and receiving aged care ‘including people receiving end-of-life care, the right to fair, equitable and non-discriminatory access to palliative and end-of-life care’.
- » A review and update of the Aged Care Quality Standards including incorporation of palliative care. This will ensure that aged care providers have clear regulatory requirements to provide palliative care in their services.



“It is very clear that our calls for palliative care to be considered core business in aged care have not just been heard, not just understood but in fact fully embraced.”

Professor Meera Agar
Chair, Palliative Care Australia



- » Compulsory palliative care and dementia care training for aged care staff. This will ensure the aged care workforce is suitably trained and skilled to meet the needs of those receiving aged care services, including those who have palliative care needs.
- » Empowering the Australian Institute of Health and Welfare (AIHW) to undertake aged care data governance, including coordinating, collecting, storing, standardising, sharing and publishing aged care related information and statistics. This includes developing and publishing a National Aged Care Data Asset comprised of a number of national minimum aged care datasets. PCA believes this improved data collection should also include comprehensive and uniform data relating to palliative care.

Priority for assessment, referral and access to services

Many Australians experience long delays when waiting for an assessment for aged care services and while waiting to access those services. These long delays mean that people with life-limiting illnesses and their carers may miss out on a service because they may die before they are even assessed for services. There are several ways in which people receiving palliative care could be supported in the aged care assessment pathway:

- » **Urgent referral to home support services:** when a person first registers for an assessment with My Aged Care, there is an option for them to be referred immediately to a service provider to receive time-limited support before receiving an assessment if the client has an 'immediate health or safety intervention that cannot be supported by other means'. People with a terminal diagnosis of less than three months should be eligible for this immediate referral.

- » **Priority for referrals:** a referral for assessment includes a priority rating that relates to the timing of the assessment and is based on factors such as a client's level of function and the risk in relation to the care situation. This priority process does not factor in if a person has a life-limiting illness and may die before being assessed for services. People with a terminal diagnosis of less than six months should be given the highest priority level for an assessment.
- » **Priority for services:** if a person receives an assessment for a home care package and they are found eligible, they will enter the National Prioritisation System. The person's priority in the system is determined by the date they were approved and the priority given by the ACAT during the assessment. The priority process is the same for referral, with an emphasis on the client's level of function and risk. People with a terminal diagnosis of less than six months should be given the highest priority level when entering the National Prioritisation System.

Aged Care Funding

Currently, palliative care is not appropriately recognised and funded in aged care. The Aged Care Funding Instrument (ACFI), which is currently used to determine levels of funding in residential aged care only funds 'palliative care' at the 'end-of-life' where the definition of end-of-life is referenced as the 'last week or days of life', which only enables providers to claim for:

"Palliative care program involving end-of-life care where ongoing care will involve very intensive clinical nursing and/or complex pain management in the residential care setting."

Accordingly, palliative care services in residential aged care are under-serviced and under-funded, with only one in 50 permanent residents receiving ACFI-funded palliative care. Home Care Packages funding does not provide any additional funding to support care recipients who are palliative, including purchasing equipment. Providers must find funds from within the home care package funds currently being received for the client.

Under the new residential aged care funding instrument, the Australian National Aged Care Classification (AN-ACC) scheduled for implementation for 1 October 2022, there is potential to better fund aged care providers to deliver palliative care. The pricing schedule needs to be strongly linked to the Aged Care Quality Standards and the Aged Care Act to ensure providers are fully funded for all their regulatory obligations and residents for the care they are entitled to. It will also need to fund the required 200 care minutes per resident per day (include 40 minutes of registered nurse care). These care minutes are crucial in ensuring that there is adequate staffing available to meet the palliative care needs of residents. In relation to palliative care, the pricing schedule will need to consider adequate funding to provide:

- » Clinical care to people receiving palliative care, including pain relief and management and a suitable level of qualified registered nurses.
- » Equipment to support people receiving palliative care needs.
- » Support to have discussions around death and dying and undertake Advance Care Planning, including preparing documentation and uploading to My Health Records.
- » Care that meets the cultural, religious, social, emotional and spiritual needs of the individual.
- » Support for families and carers.
- » Counselling and grief and bereavement support for residents, families and staff

The introduction of a new home support program in 2023 will also need to ensure adequate funding to provide palliative care services for those wishing to stay at home. This should include coordination with other community and health services to provide a holistic, integrated package of care targeted to each individual.

Specialist Palliative Care Services

The Royal Commission raised concerns around the fragmentation of the aged care system and the passing of responsibilities between the aged care and health system. This can significantly affect the ability of residents to access the care that they need.

The Royal Commission recommended that the Australian and state and territory governments amend the National Health Reform Agreement to include:

- » an explicit statement of the respective roles and responsibilities of approved aged care providers and state and territory health care providers to deliver health care to people receiving aged care (including responsibility for specialist palliative care services sitting with State and Territory health care providers); and
- » explicit commitments by state and territory governments to provide access by people receiving aged care to state and territory government-based health services (including palliative care services).

The Government accepted these recommendations in principle, noting that they will involve consultation with state and territory governments. The Government must commit to the ongoing work this will involve, including extensive negotiation and relationship building.

DISABILITY

Accessing the NDIS

The majority of people under the age of 65 with a life-limiting illness cannot access aged care services and must rely on the National Disability Insurance Scheme (NDIS) for support services such as allied health and other therapies, personal care, aides and equipment and home modifications.

Many Australians experience long delays when waiting to access NDIS services. These long delays mean that people with life-limiting illness and their carers may miss out on a service because the person may die before they are even assessed for services. There is no clear pathway for people receiving palliative care to access the NDIS and receive services in a timely manner.

Providing a NDIS palliative pathway could better support people receiving palliative care to access services in a timely manner. A specialised palliative pathway would allow for expedited access requests, approvals for access and planning processes. This expedited access to NDIS services would also reduce carer burden and hospital admissions and ensure people could continue to stay in their homes.



PALLIATIVE CARE FOR ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLE

When Aboriginal and Torres Strait Islander people are diagnosed with a life-limiting illness or are approaching the end of their life, they should be able to access quality palliative and supportive care that is consistent with their wishes, when and where they need it, no matter where they live. Importantly, this care must be culturally safe, appropriate and responsive, incorporating the social, emotional, and cultural well-being of the person, as well as their family and the community.

Aboriginal and Torres Strait Islander people are currently underserved when it comes to palliative care services and when they do access services, many are not culturally safe and response services. The development of a palliative care action plan for Aboriginal and Torres Strait Islander people is a first step in ensuring that palliative care meets Aboriginal and Torres Strait Islander people's needs. This would lead to the development of culturally appropriate care models, support for Aboriginal and Torres Strait Islander workers, cultural awareness training and support for culturally appropriate advance care planning.

The Royal Commission expressed the strong need to support Aboriginal and Torres Strait Islander people and ensure that the new aged care system makes specific and adequate provision for the diverse and changing needs of Aboriginal and Torres Strait Islander people. The Government has accepted these recommendations with the establishment of an Aboriginal and Torres Strait Islander specific pathway that includes assistance in accessing assessment and services, development of culturally appropriate models of care and support for Aboriginal and Torres Strait Islander organisations and workforce to deliver care.

It is crucial that Aboriginal and Torres Strait Islander people are active partners in building a better palliative care system and are involved in the development of any programs and care pathways.

WORKFORCE

Currently, there are 292 palliative medicine physicians and 3,658 palliative care nurses across Australia (1.1 and 12.4 full-time equivalents per 100,000 population, respectively)²⁶. There is a need to support additional palliative medicine trainee positions in Australia, particularly in rural and regional areas.

The Palliative Care Service Development Guidelines set a benchmark of 2.0 full-time equivalent Specialist Palliative Medicine Physicians per 100,000 population. This means that by 2030, with an expected population of 30 million, Australia should be aiming for 600 Specialist Palliative Medicine Physicians. This is more than double the current number. In addition to these benchmarks, workforce modelling should forecast the increase in the size and diversity of the Australian population to ensure there is an adequate workforce to meet these population needs. The modelling should be revisited on a regular basis.

The lack of accurate data around the current palliative care nursing workforce makes it difficult to project the exact need. Despite this, we know that a substantial increase is required to meet increased demand due to the ageing population and increased rates of chronic illness and complex comorbid illness. Modelling work needs to be undertaken to determine the need for nurses and set ratios for palliative care and community nursing.

Nursing is ideally positioned to lead in the care of people with advanced serious illness. A proportion of these nurses need to be specialist palliative care nurses. However, all nurses (specialists and non-specialist) need resourcing and skill development in order to enable optimal care. Nurse Practitioners are uniquely positioned to make a large difference in enabling equitable care given their ability to work across care settings and across all locations, including metropolitan,

rural and remote. Again, some of these will be specialist palliative care Nurse Practitioners, and some will be Nurse Practitioners working in other areas, including aged care and primary care, but who will provide extensive support for people with advanced serious illness. All Registered Nurses and Nurse Practitioners need appropriate resourcing and support to enable optimal care to people who are palliative, including supportive models of care. This can be further supported by increasing Medicare MBS rebates for Palliative Care Nurse Practitioners to support the delivery of palliative care services, especially in aged care, rural and remote areas and for those working with Aboriginal and Torres Strait Islander Communities

With the introduction of mandated care minutes in aged care, including registered nursing care, there will need to be a significant increase in the aged care workforce. This workforce needs to be adequately trained and resourced to deliver palliative care. This increase in the aged care workforce and care minutes should also include minimum staffing available 24 hours a day to make clinical decisions and give medicines when people need them.

RESEARCH

Australia has benefited from a strategic investment in palliative care projects, which has created a large network of clinicians, academics, researchers and policymakers, and has funded initiatives such as the Palliative Care Outcomes Collaboration (PCOC), CareSearch, and the Palliative Care Clinical Studies Collaborative. The research outcomes from these networks have contributed significantly to the quality of palliative care provided in Australia.

However, to meet the emerging palliative care clinical and policy challenges, a stronger focus on palliative care research priorities and increased investment in research is needed. This will assist

in developing the optimal evidence to inform interventions and services. Research that is specifically focused on palliative care for older Australians, including those living in residential aged care, must also be a priority.

Palliative care research can be best supported by committing dedicated specific funding for palliative care research from the National Health and Medical Research Council (NHMRC) and the Medical Research Futures Fund (MRFF) grants. This will also support Goal 6 of the *National Palliative Care Strategy 2018*²⁷, which focuses on data and evidence, including a robust national research agenda that informs sector development and improvement.

Funded research could include:

- » the benefits of early referral to specialist palliative care for non-malignant life-limiting illnesses,
- » the off-label use of medicines,
- » systems to monitor and record improvements or changes in quality of life, avoidance of clinically non-beneficial treatments and ICU presentations, life expectancy and experiences of the person and their carers working within different models of care and at different points in the illness trajectory,
- » dementia and palliative care research,
- » palliative care for people with multimorbidity and frailty,
- » palliative care for people living with a disability,
- » palliative care for Aboriginal and Torres Strait Islander people, and;
- » palliative care for Culturally and Linguistically Diverse (CALD) people.



DATA AND REPORTING

In order to better fund and plan for palliative care, it is important that we understand current activity and expenditure to determine funding levels are sufficient and if there are any gaps or overlaps in service provision.

In 2021, PCA commissioned KPMG to produce the follow-up report *Information gaps in Australia's palliative care*²⁸, to explore the existing evidence on palliative care funding and provision across Australia. KPMG found that reporting of palliative care activities and expenditure in Australia ranges from excellent to non-existent. This makes it difficult to determine the current levels of palliative care services and funding, identify gaps or areas of overlap and evaluate and track progress over time. Palliative care data is not consolidated or accessible, and the consistency of reporting is poor.

Without targeted data collection and better linkages, Australia is not able to adequately analyse how many people are accessing palliative care services and in what settings, the demographics of those accessing care, and their preferences for place of care and place of death. This data is essential for governments to adequately plan for, and invest in, palliative care needs into the future.

Development of a National Palliative Care National Minimum Data Set (NMDS) that includes health, paediatric, and aged care data will allow for the collection of uniform data and reporting at a national level. This further supports Goal 6 of the *National Palliative Care Strategy 2018*²⁹, which focuses on research and data, including nationally consistent data collection and reporting.

Increased funding for the Australian Institute of Health and Welfare (AIHW) to would support them to manage increased data collection in palliative care and aged care, including the development of data sets.

GRIEF AND BEREAVEMENT

The COVID-19 pandemic has shown the significant role that palliative care has in supporting COVID-19 patients and people who are seriously ill or dying and their families. Further, there are likely to be a number of long term impacts relating to grief, bereavement and mental distress for residents, patients, family and staff in health and aged care as a consequence of the pandemic.

It is estimated that 44,000 Australians will be diagnosed with prolonged grief disorder each year.³⁰

As part of its planning and leadership for the palliative care sector during the COVID-19 pandemic, PCA held two strategic forums in 2020 with experts in palliative care, grief, bereavement and mental health to identify the emerging issues, available resources and gaps in current service provision³¹. The primary recommendation from these forums is the development of a National Framework for Disaster Grief, Bereavement and Mental Health to bring together currently siloed aspects of services in mental health, specialist palliative care, community health and primary care; to optimise integration and referral pathways and to minimise gaps. This could be further supported by the development of national standards for bereavement service provision in Australia.

OPIOIDS

Appropriate access to opioid medication is critical to managing and relieving pain and symptoms associated with a life-limiting illness, such as chronic breathlessness.

A number of Australian health professional bodies have co-signed the Position Statement: Sustainable Access to Prescription Opioids for Use in Palliative Care³², which recognises the need to increase knowledge about appropriate use of opioids within the Australian palliative care context while providing leadership and guidance in the regulatory processes for the community and prescribers³³. It supports safe, evidence-based, and appropriate clinical oversight of opioid prescribing in palliative care while recognising legitimate concerns related to inappropriate use and prescribing in other clinical settings.

PCA acknowledges that the Department of Health has made funds available under the National Strategic Action Plan for Pain Management for the development and provision of pain management training and educational resources for medical practitioners. This is further complemented by the Opioids Education Program delivered by NPS MedicineWise to increase GP knowledge and awareness, improve the quality of opioids, and reduce harm for Australians with chronic non-cancer pain (CNCP).

PCA calls for the above education to be supplemented by more specialised training in the evidence-based use of opioids aligned with the updated evidence-based cancer pain and palliative care guidelines³⁴. This will optimise opioid management for those for whom the evidence supports benefits. It will also ensure medical practitioners are enabled to prescribe, in a timely manner, appropriate opioids for pain and breathlessness management for those with palliative care needs and to refer to specialist support where necessary.

CARERS

A person and family-centred approach to palliative care and end-of-life care accepts that an illness has an impact on both the individual and their family and carers. The extent and quality of support provided to the carer and the person nearing the end of life is key to the experience they both have. Carers need support to allow them to provide care in a manner that also promotes their health, well-being, and personal aspirations. This includes:

- » improved access to timely in-home support,
- » early identification of carer's emotional and physical health needs, including during bereavement,
- » addressing carers' needs for greater financial support,
- » carer-sensitive workplace policies,
- » timely access to respite services,
- » expediting claims through Services Australia, NDIS and My Aged Care.

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- » Carers Australia
- » Australian Health and Hospitals Association (AHHA)
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- » Pain Australia
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