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!*

Version 2.0 Updated February 2023

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.

Contents

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 specialist palliative care, primary care and acute and subacute 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.
- Implement the Paediatric Palliative Care National Action Plan.
- Investing in palliative care advocacy and awareness campaigns to raise community awareness about death, dying, grief 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 2050.[1] 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 hospitals 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. As voluntary assisted dying is implemented, research and data collection will be vital in understanding the impact on palliative care.

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 unit[2], and those that do 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 professionals. 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]
>
> World Health Organization

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 supports people to 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.

PalliativeCare AUSTRALIA

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.

PCA Roadmap 2022–2027

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. Assisting a person to undertake advance care planning helps them to communicate their preferences and future treatment decisions.

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 symptoms like pain, fatigue and breathlessness; and optimises function and supports participation in what is important to the individual.

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.

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	
» 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: – $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 days.[6] * – $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.* Note: Figures as per the KPMG report[7] » 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.* » Increase in investment to support integrated care across national and state/territory health systems. » Funding models for acute care updated to include resources to deliver bereavement care to families and loved ones after a person's death. » 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. » 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.	Increase the funding per year for residential aged care to: » $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, including all allied health disciplines, 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.

*Included in May 2023 pre-budget submission

INVESTMENT *(continued)*

INVESTMENT

Workforce

IMMEDIATE 2022-2024	SHORT TO MEDIUM TERM 2025-2027
» $2.75 million over 3 years to fund the development of a National Palliative Care Workforce Plan that includes strategies for increasing the workforce and succession planning.*	» Increase in the palliative care workforce in line with modelling including, at a minimum: – A substantial increase in specialist palliative medicine physicians, 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, palliative care nurse practitioners and allied health professionals should be commenced.
» $20.1 million over 3 years for palliative care training for Registered Nurses in residential aged care.*	» 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.
» 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.	» Establishment of a mentoring program to provide support to the emerging palliative care workforce.
» 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.	» All undergraduate training in medicine, nursing and allied health includes content on dying, grief and bereavement and palliative care.
» IN PROGRESS Training for General Practitioners to better understand palliative care and support patients through their palliative are journey.	

Research and Data

» Australian Government commits a minimum of $10 million per year dedicated to palliative care and end of life research, this will be particularly important with voluntary assisted dying legislation being implemented or progressed across all states and territories.	
» Establish a Palliative Care National Minimum Data Set for health, aged care (residential and home care) and paediatrics.	
» Provide 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.	

*Included in May 2023 pre-budget submission

INVESTMENT

IMMEDIATE 2022-2024	SHORT TO MEDIUM TERM 2025-2027
Advocacy	
» Fund PCA for $1.2 million over 3 years in core peak funding to support its advocacy for palliative care. This advocacy is critical to drive national improvements in, and access to, palliative care.* » Immediately increase funding to improve community awareness around death, dying, grief and palliative care, including: – Funding for Palliative Care Australia to extend radio and TV public awareness 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	
» 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 (including an assessment by an Occupational Therapist), information, education and resources. » Early identification of carers' emotional and physical health needs, including during bereavement.	
Paediatric	
» Implement the Paediatric Palliative Care National Action Plan.	

*Included in May 2023 pre-budget submission

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 need timely access to aged care and NDIS services

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

AGED CARE

IMMEDIATE 2022-2024	SHORT TO MEDIUM TERM 2025-2027
» IN PROGRESS The new Aged Care Act incorporates palliative care. » IN PROGRESS Aged Care Quality Standards reviewed and updated, including standards relating to the delivery of palliative care. » Ongoing review of aged care reform, in particular to identify undesirable consequences.	» All home care services that provide palliative and end-of-life care are accredited by the Australian Government.
Service Delivery	
» All aged care providers deliver palliative care as per the updated Standards and Act. » 2023 – the new in-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 from time of diagnosis and to ensure implementation of the National Dementia Action Plan in 2023-2024.	» The National Health Reform Agreement updated 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; 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	
» People with a prognosis of less than three months are eligible for immediate referral to services by My Aged Care. » People with a prognosis of less than six months are given the highest priority level for an assessment. » People with a prognosis of less than six months are given the highest priority level when entering the National Prioritisation System.	

AGED CARE *(continued)*

AGED CARE

IMMEDIATE 2022-2024	SHORT TO MEDIUM TERM 2025-2027
Training	
» ACHIEVED 2022 Updated Certificate III in Individual Support includes compulsory palliative care and dementia units for those undertaking the Aged Care specialisation. » 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. » Implementation of palliative care training for all Registered Nurses employed in residential aged care as the 24/7 nurses requirement is implemented.*	» 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: – 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	
» IN PROGRESS 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	
» IN PROGRESS Department of Health to set a AN-ACC pricing schedule that funds providers to deliver palliative care. » ACHIEVED 2022 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. » IN PROGRESS 2023 – The Independent Hospital and Aged Care Pricing Authority (IHACPA) to continue to review the AN-ACC pricing schedule, ensuring a link with the newly updated Standards. » ACHIEVED 2023 2023 – IHACPA sets a price that fully funds the care at home palliative care category.	

*Included in May 2023 pre-budget submission

	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

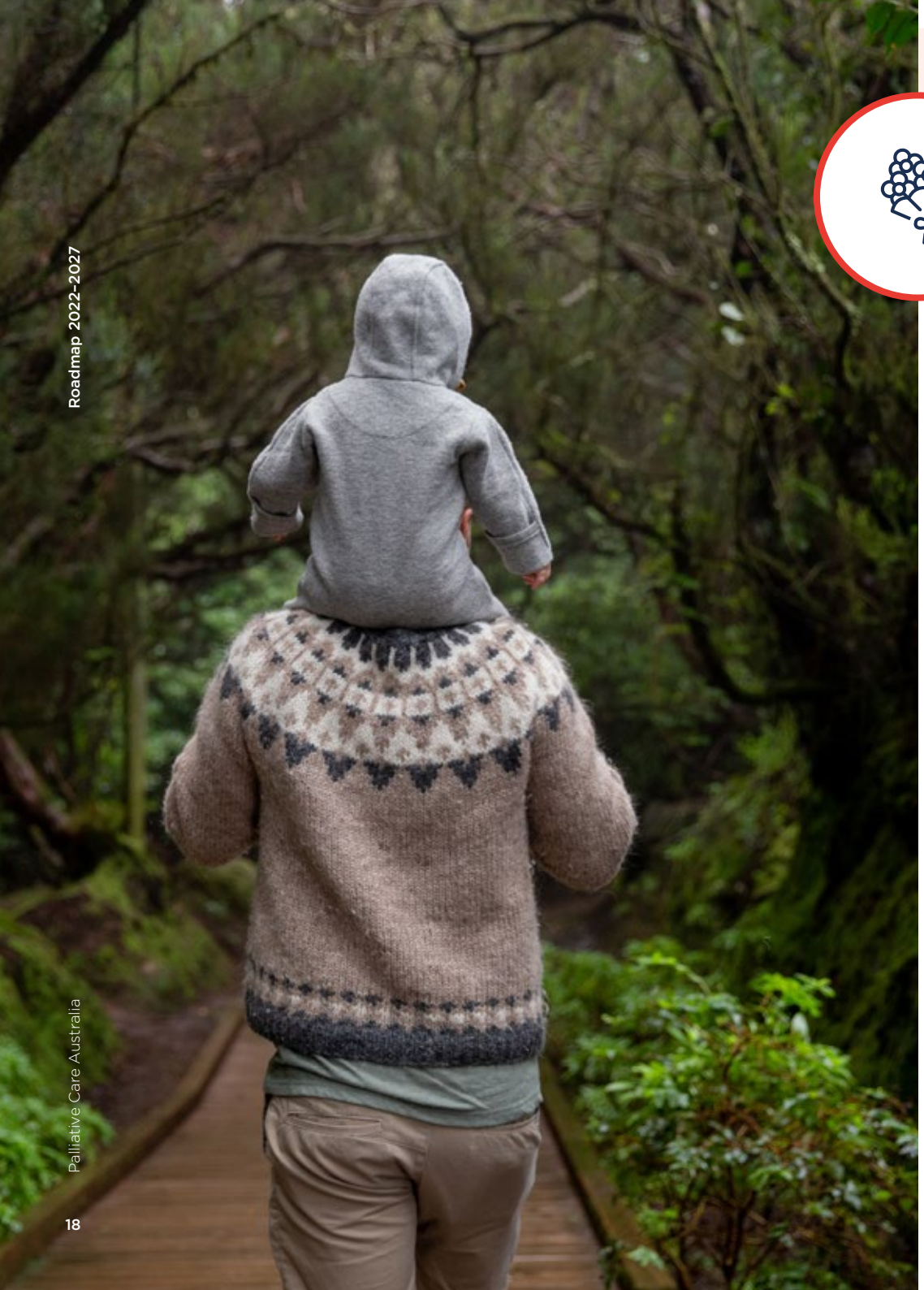
ISSUES TO ADDRESS

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

MEDICINES

IMMEDIATE 2022-2024	SHORT TO MEDIUM TERM 2025-2027
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. » 2023 -Implementation of the planned introduction of on-site pharmacists in residential aged care homes in response to the Royal Commission into Aged Care Quality and Safety, Recommendation 38.	
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
	» Finalisation and implementation of death and dying principles and practices in the pending National Disaster Mental Health and Wellbeing Framework. » 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 and access to social work and counselling services.	» 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

ABORIGINAL AND TORRES STRAIT ISLANDER PALLIATIVE CARE

IMMEDIATE 2022-2024	SHORT TO MEDIUM TERM 2025-2027
» Immediately fund the development of a National Palliative Care Action Plan for Aboriginal and Torres Strait Islander People, to be led by an Aboriginal community-controlled organisation. » Development of culturally appropriate care models to support Aboriginal and Torres Strait Islander people living with a life-limiting illness. » 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.	» Implementation of culturally appropriate care models to support Aboriginal and Torres Strait Islander people living with life-limiting illness. 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. » IN PROGRESS 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. » IN PROGRESS 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 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 Australia[8].

» 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 it[9].

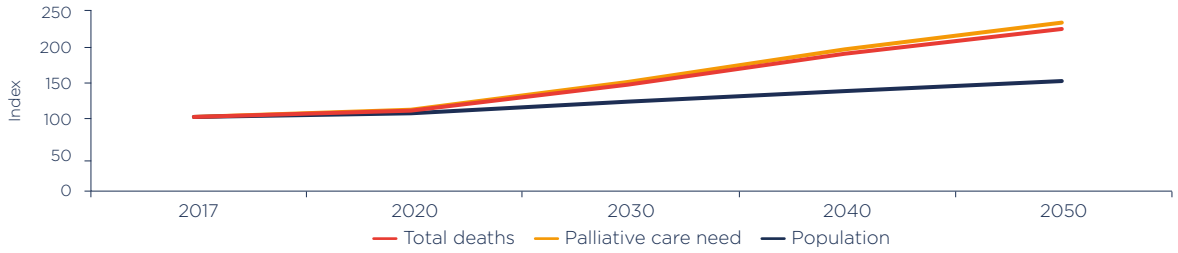
» Between 2017-2020, the proportion of patients and families referred to specialist palliative care by general practitioners has remained constant. This suggests that more needs to be done to increase referrals from primary care to specialist palliative care[10].

» 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 issue[11].

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 care[12]. 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 services[13].

» 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 funding[14].

Residential Aged Care

» There is a substantial unmet need for palliative care in RACFs. Over 53% of residents have high complex health care needs[15], and there are over 53,000 deaths in RACFS each year[16]. 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 RACFs[17].

» 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 population[19].

Workforce

» While demand for palliative care has been growing at over 3% per annum over the last five years[20], the number of palliative care nurses have grown at 2% per annum[21], 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 resources[22].

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.
- $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 increased 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 year[23].

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.

AGED CARE

Palliative Care in Aged Care (as at 2022)

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 care[24], 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.

- 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 was used until 2022 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."*

"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

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 2024 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, specifically Occupational Therapy and Physiotherapy, 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 responsive 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

The palliative care workforce, and health workforce more broadly is in crisis. Support is needed urgently to assist in the development of a new workforce and to ensure sustainability of the wisdom and experience that is currently in the sector, across all disciplines.

As at 2022 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.

The lack of modelling and data on workforce extends to allied health professionals. The important role of each allied health profession is outlined in PCA's Palliative Care Service Development Guidelines.[27] The scope of allied health clinical practice in palliative care has increased significantly over the last 10 years, as more allied health professionals provide care for people with palliative care needs outside specialist palliative care. As people are living longer and there are limited numbers of specialist palliative care teams there is an increased need for allied health professionals. Allied health professionals including but not limited to Physiotherapists, Occupational Therapists, Psychologists, Social Workers, Dieticians, Speech Pathologists and Arts and Music Therapists provide clinical support to people with sustained rehabilitative needs to optimise function/reduce physical burden on carers and improve quality of life.

PCA acknowledges that working with volunteers is a consistent and valued feature of providing palliative care in Australia. Volunteers provide support for the professional workforce and resourcing is required to ensure volunteers are trained, managed and coordinated.

The concept of 'communities of care' acknowledges the role and value of both the informal and formal networks of care and the natural supports that exist in our communities, and incorporates those who make up the paid and unpaid palliative care workforce, such as specialist, generalist, or community care providers and families, loved ones, volunteers, carers, and community support networks.

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*[28], 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 benefits of early, multi-disciplinary palliative care, particularly in primary care,
- 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*[29], 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*[30], 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

It is estimated that over 44,000 Australians will experience prolonged grief each year.[31] As such PCA endorses a population approach to bereavement and advocates for the development of national standards for bereavement service provision in Australia.

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.

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 provision[32]. 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.

Another emerging need is people who are bereaved because of a loved one accessing voluntary assisted dying. Further research is needed as voluntary assisted dying is implemented across the jurisdictions to better understand the impacts on family, loved ones and medical professionals.

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 Care[33], 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 prescribers[34]. 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 and Aged Care 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 guidelines[35]. This will optimise opioid management for those for whom the evidence supports should benefit. 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, loved ones 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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ACKNOWLEDGEMENTS

Palliative Care Australia would like to acknowledge all those individuals and organisations that contributed to the development of the Roadmap. This includes:

» Palliative Care Australia Board

» Palliative Care Australia former Election Advisory Group

» Palliative Care Australia Member Organisations

» Australian and New Zealand Society of Palliative Medicine (ANZSPM)

» Palliative Care Nurses Australia (PCNA)

» Palliative Care Social Work Australia (PCSWA)

» Paediatric Palliative Care Australia & New Zealand (PaPCANZ)

» Indigenous Allied Health Australia (IAHA)

» National Aboriginal Community Controlled Health Organisation (NACCHO)

» Dementia Australia

» Carers Australia

» Australian Health and Hospitals Association (AHHA)

» National Rural Health Alliance (NRHA)

» Pain Australia

» Australian Nursing and Midwifery Federation (ANMF)

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