

2024 Federal Budget Submission



PalliativeCare
AUSTRALIA

Matters of  life and death

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What is palliative care?

Palliative care aims to improve the quality of life for people living with a life-limiting illness. Palliative care is a holistic public health based approach to individual needs that treats symptoms which are physical, emotional, spiritual, and social.

A range of health professionals play their role, as well as members of the community. Palliative care is a family-centred model of care, meaning that family and carers can receive practical and emotional support.

Who is Palliative Care Australia?

Since 1991, Palliative Care Australia (PCA) has been the national peak body for palliative care.

We represent all those who work towards the delivery of high quality palliative care to people with a life-limiting illness as well as support for their carers and loved ones.

Professionals in the health, aged care, and community sectors are at the heart of this work.

Palliative Care Australia's Member Organisations



Acknowledgement of Country

Palliative Care Australia is located in Canberra. We acknowledge the traditional custodians of the surrounding land and waters the Ngunnawal and Ngambri Peoples and pay our respects to Elders past and present. We honour and value their continuing culture and the contribution they make to the life of this city and this region.

PCA investment priorities: 2024-2025

Better access to palliative care for now and the future

Policy area	Responsible agencies	Recommendations	Budget implications
Palliative care at home for people under 65	<div>NDIA →</div> <div>DoHAC</div> <div>DSS</div>	The NDIA or another Australian Government agency should make funded supports available to people who would otherwise be successful in gaining access to the NDIS, but are being rejected solely because of a short life expectancy, via 3-month rapid access packages for people with a life expectancy of less than 12 months.	Cost neutral if funded through NDIS
	<div>DoHAC →</div> <div>DSS</div>	The Australian Government should establish a new program of non-clinical support for people under 65 with a disability associated with a life-limiting illness who need functional support to remain at home, and who cannot access this support through the NDIS or State/Territory-funded services. The program should be established on an interim basis for 2 years, or until a lasting solution has been found. It could be managed by Palliative Care Australia via a grants program to commission appropriate services from registered providers. URGENT PRIORITY 2024-25	\$77.6 million over three years, with two years of delivery*
	<div>DoHAC →</div> <div>DSS</div>	The Australian Government should commission research to map non-clinical support services currently available through different systems for people under 65 with life-limiting conditions, and to identify gaps in services that support people to remain at home and out of hospital.	\$800k*
	<div>DoHAC →</div> <div>DSS</div> <div>S/T Health</div>	Governments should provide a clear resolution of the respective roles of different tiers of government and different portfolios regarding responsibility for the delivery of non-clinical support services for people under 65 with life-limiting conditions. This should occur both through the National Health Reform Agreement, and, as recommended by the Independent Review of the NDIS, a new system of 'foundational disability supports' including 'state and territory home and community support programs to provide additional support to people with disability outside the NDIS'.	To be determined when further govt decisions are made
	<div>NDIA →</div>	NDIA should convene a time-limited advisory group to provide advice to the NDIA on how its existing approaches to the assessment of access requests and to planning can be adapted to better meet the needs of people with life-limiting conditions.	Cost neutral
Aged care	<div>DoHAC →</div>	The Department of Health and Aged Care should require that all aged care residents receive a palliative care assessment upon entry into residential aged care facilities. Further, if a resident is classified as palliative, this status should be retained for the duration of that person's care, and appropriate palliative care provided.	Cost neutral
	<div>DoHAC →</div>	The Department of Health and Aged Care should re-evaluate the applicability and usefulness of AN-ACC Class 1 (Palliative Care) in reflecting the full costs of care of those in residential aged care who are palliative.	Cost neutral

Policy area	Responsible agencies	Recommendations	Budget implications
Aged care	DoHAC →	The Australian Government should establish a new stream for palliative care in the new Support at Home Program, to prioritise rapid access to care at home for people who have very significant palliative care needs.	Costing work by government underway
	DoHAC → S/T Health	The Australian Government should continue matching State/Territory funding for the Comprehensive Palliative Care in Aged Care Measure beyond the current project completion date of June 2024. It should also identify performance measures for the future National Health Reform Agreement to make funding for palliative care in aged care ongoing and to promote accountability. URGENT PRIORITY 2024–25	At least \$33 million over 3 years to match current funding levels, funding matched by States/ Territories
National coordination and data	DoHAC → S/T Health	The Australian and State/Territory Governments should re-establish a high-level governance structure to oversee work under a refreshed National Palliative Care Strategy Implementation Plan, including critical data development work.	Cost neutral
National Health Reform Agreement	DoHAC → S/T Health IHACPA	The Australian and State/Territory Governments should request that IHACPA investigate how to build incentives for community-based palliative care into future pricing models, taking into account the financial savings associated with avoiding potentially preventable hospital admissions and ED presentations for people in their last year of life.	Cost neutral
After hours access	DoHAC → S/T Health	The Australian Government should fund a gap analysis to identify variability in access to after-hours palliative care nationally, and seek support from States and Territories to address gaps in after-hours access under a refreshed National Palliative Care Strategy Implementation Plan. URGENT PRIORITY 2024–25	\$300k initially, then S/T investments*
	DoHAC →	The Australian Government should establish a national 'Palliative Care Aware' initiative for community pharmacy by funding the broader rollout of the Queensland Health "palliPHARM" pilot, which promotes priority access to palliative medications and personal care supplies after hours.	\$3.1 million over three years*
Sector support	DoHAC → NT Health	The Australian Government should fund further work to improve access to quality palliative care for Aboriginal and Torres Strait Islander Australians and to build the capacity of the palliative care sector in the Northern Territory. This should include matched Commonwealth/Northern Territory funding to support a peak body for the palliative care sector in the Northern Territory.	\$900,000 over 3 years*
Cancer care	DoHAC →	PCA encourages the Australian Government to work with partners to ensure palliative care is fully integrated into the new Australian Cancer Nursing and Navigation Program, including in outcomes measures, particularly within the new national all-cancer nursing service.	Cost neutral

* Further information on PCA's costings can be made available upon request.

1.0 Background

1.1 Introduction

Palliative care helps people live as well and comfortably as possible with a life-limiting illness. The number of people living longer, and dying, with life-limiting illnesses is increasing year on year.¹ Demand for palliative care is expected to double by 2050.² There is a need for immediate and continued investment in this area, both to meet the changing demographic profile and health needs of Australians, and because equitable access to timely palliative care is essential to a high-performing and cost-efficient health system.

The overarching theme for PCA's Budget Submission is *Support at home for people with life-limiting conditions*. When asked, most Australians say they would prefer to spend the last months and weeks of life at home if possible. But this goal can be elusive, for complex reasons including changing circumstances and preferences as an illness progresses, demands on carers and families, and challenges in getting different systems to work well together.

Palliative Care Australia's proposals are based on the following principles:

- ♥ People with life-limiting conditions should be supported to be as independent as possible, and to remain at home if safe and practical. This means reducing or avoiding unnecessary hospital stays.
- ♥ People with life-limiting conditions should have access to appropriate planning and support regardless of age, location, or life expectancy. Where it is clear someone with a life-limiting illness needs support, but unclear which system has responsibility for providing support, services should be made available as rapidly as possible. Sorting out which system pays should be a matter for governments to administer behind the scenes, and not the responsibility of people with serious conditions or their carers.^a
- ♥ All government agencies involved in the delivery of services to vulnerable people have a responsibility to actively manage interfaces between systems (such as aged care, health, housing, and disability) with the aim of ensuring barriers to fair and equal access are removed.^b

^a This reflects Jordan's Principle, legally enshrined in Canada, which holds that First Nations Canadian children should not be denied access to public services while governments fight over who should pay.

^b The Royal Commission into Aged Care Quality and Safety, Recommendation 4, sets out this principle in relation to the Department of Health and Aged Care's stewardship of the aged care system. The National Health Reform Addendum Schedule F and NHRA Long-Term Reform Roadmap set out a commitment from all Australian governments to improve interfaces between health, disability, and aged care systems.

1.2 Why support at home?

Home- and community-based palliative care should be high-quality, safe care that allows people to live well and remain at home for as long as possible with optimal management of their symptoms. Most people with life-limiting illnesses have non-complex care needs that can mostly be met in primary care settings.³ Specialist outreach palliative care teams deliver essential care for people with more complex needs,⁴ including in their own homes and other residential settings, including residential aged care.

People with life-limiting illnesses who receive palliative care at home and in the community have fewer hospital admissions, shorter stays in hospital when admitted, spend less time in Emergency Departments and Intensive Care Units, and use ambulance services less frequently. This delivers significant cost savings to the health system. Every dollar invested in **home and community based palliative care** delivers a 100% return on investment.⁵

People who receive integrated home-based palliative care:

- ♥ Visit an Emergency Department between two and 12 per cent less in their last year of life (when compared with people with life-limiting illness who don't receive care at home).
- ♥ Have a reduction in days spent in hospital in their last year of life, of between 4.5 and 7.5 days.
- ♥ Are twice as likely to die at home.⁶

Investment in **integrated home-based palliative care models** is cost neutral, on average – each dollar invested returns between \$0.53 and \$1.56⁷

When asked, most Australians say they would prefer to spend the final weeks and months of life at home.⁸ Substantial evidence indicates the benefits for people and families in remaining at home as long as possible.⁹ Demand for home and community-based models is increasing rapidly as a component of overall swift growth in need for palliative care, which is expected to double by 2050.¹⁰

Commonwealth and State/Territory Governments have already agreed that keeping people at home where possible is good policy as well as good practice. It also makes economic sense, because diverting people from avoidable hospitalisations or other treatments as well as implementing advance care planning saves money. Keeping people over 65 at home for as long as possible is also now a key tenet of aged care reform, for similar reasons.

- ♥ The National Palliative Care Strategy sets the aim of “supporting people to stay at home longer”¹¹ and commits governments to “continue to support and develop community-based palliative care services”.¹²
- ♥ Aged care reforms currently underway recognise that “most people want to stay in their homes for as long as possible, and value the services that allow them to do this”¹³ including when needs associated with frailty and/or life-limiting illness become complex and people require more support to stay at home.¹⁴
- ♥ In residential aged care, palliative care is recognised as “core business” with many recommendations of the Royal Commission into Aged Care Quality and Safety still in early implementation phase.¹⁵

The National Palliative Care Strategy priorities include:

- People can receive timely palliative care in the place of their choice.
- Carers get the support they need, including in-home support, respite care and bereavement support.¹⁶

Home and community-based palliative care aligns with community and patient expectations and is a high performing and efficient approach to care. Yet too few people with life-limiting illnesses receive it.

- ♥ In 2021-22 fewer than five per cent of MBS-funded palliative care specialist consultations were home visits.¹⁷
- ♥ While estimates vary, between four¹⁸ and 14 per cent¹⁹ of people in Australia die at home, in contrast to the expressed preference of the majority.²⁰
- ♥ In 2022, just under half of all reported palliative care episodes were provided in community settings.²¹
- ♥ In 2022, of 61,100 patients receiving palliative care nationally only 22 per cent died at home.²²
- ♥ The number of palliative medicine specialists nationally falls short by at least 50 per cent – a significant barrier to provision of palliative care at home.²³

The National Palliative Care Strategy acknowledges that “investment is needed into community-based models that are flexible to accommodate increased demand and public expectations”. This requires resources, infrastructure, technology, and carer support.²⁴

Home-based palliative care:

- Supports patients who wish to be cared for at home for as long as their needs can be met, and where possible, to die in the place of their choice.
- GPs play an important role to identify palliative care needs, and to provide care such as symptom management, case conferencing and support for advance care planning, care coordination, after-hours support and counselling, spiritual and psychosocial support.
- Is a model of care that supports individuals, families, and caregivers outside institutional settings.

Integrated home-based palliative care:

- Involves a multidisciplinary team led by a GP.
- The team may include nurses, allied health, volunteers, and other community workers.
- Patients may have access to specialist palliative care support and community palliative care services where needs become complex.²⁵

2.0 Palliative care at home for people under 65

The centrepiece of PCA's Budget Submission is a new program of support for people under 65 with a disability associated with a life-limiting illness or condition who need support with the activities of daily living but cannot access this through the NDIS or other State/Territory-funded services. This issue has come to the fore recently for a range of reasons including:

- ♥ Well-intentioned efforts to divert people under 65 away from residential aged care (in response to the Royal Commission's recommendation that there should be no younger people living in residential aged care by January 2025).
- ♥ Recent changes in how the NDIA responds to access requests, which have made it harder for people with life-limiting conditions to get support from the NDIS.
- ♥ In the longer term, funding for programs which provided the kinds of services in question has been eroded. Collective decisions by governments about which systems are responsible where someone has disability support needs associated with a health condition have led to some people falling through the gaps between systems.

"We felt completely unsupported and without options."

Young mum, caring for her husband.

The recent Independent Review of the NDIS indicates that Commonwealth and State/Territory Governments are well aware of this growing problem – but that no firm solutions have yet been identified. The Independent Review's report identified the interface between the NDIS and palliative care as a "challenge that remains unresolved".²⁶ Until a solution is found, those affected will often stay in hospital unnecessarily, unless they are able to fund basic nursing and/or non-clinical supportive care out of their own pocket.

"The interface between the NDIS and palliative care can be difficult to navigate and can result in poor outcomes for people. When people are diagnosed with life threatening conditions and with very short life expectancies there is complexity as to whether support needs are best met by the NDIS or the palliative care and health system. While NDIS Rules clearly list palliative care as a health system responsibility, in practice what is palliative care and what is a disability support can be unclear or not sufficiently available, as participants may require palliative care, in addition to the functional supports to meet their lifetime disability support needs."

Independent Review of the NDIS

"People are really spending the ends of their lives ... fighting systems and trying to get support. We really need to fill this gap."

Palliative care professional

"NDIS clearly stated their position – palliative care needs are the responsibility of the health system. This created further confusion and stress for both patient and family."

Palliative care professional

"It just doesn't seem right that you can't access these things when they're meant to be available to you."

Retired nurse, living with brain cancer, being cared for by her young son.

There is an immediate need to provide the cohort in question with access to appropriate services to avoid people in vulnerable situations bouncing between the disability, health, and aged care systems during their final months and weeks of life. PCA therefore proposes an immediate response while work takes place on a comprehensive and lasting policy solution.

A key lesson from the implementation of the NDIS to date is the need to understand in detail the distinctive needs of different groups of people with disabilities across the population and the nature of the services they can (and cannot) access from mainstream systems. PCA's advice to government is therefore to take a three-stage approach, via:

- 1. An immediate rapid service response
- 2. An interim solution to address immediate and known needs.
- 3. A deliberative, evidence-informed process to identify sustainable solutions.

	Timeframe	Funding mechanism	Solutions
Short-term response	Immediate	NDIS or administered by another Australian Government Department	Rapid access 3 month package of at-home support (with automatic rollover) for people with <12 months life expectancy who would otherwise be able to access the NDIS
Medium-term response	6 months establishment 2 year program of support	Head contract between Commonwealth and PCA with funding distributed at state level	Interim program of at home support for people <65 with disabilities associated with a life-limiting condition
Long-term response	2 year development process Service funded permanently from 2027	To be agreed between governments	Research to map service gaps and identify viable solutions. System responsibilities to be agreed between governments.

2.1 An immediate rapid service response

PCA proposes that immediate and critical gaps in services be addressed by making NDIS-funded supports available to people who would otherwise be successful in gaining access to the NDIS, but are being rejected solely because of a short life expectancy.

As with all other NDIS participants, these people would still need to have a disability leading to a permanent impairment in functioning, and need disability-specific supports (that is, not healthcare and treatment) to undertake the activities of daily living. The key difference is that they would not be denied access to the NDIS purely because they are deemed by the NDIA to be palliative (for example by being in contact with palliative care services).

On a related note, people who are already NDIS participants who have a life-limiting condition should not be prevented from spending their NDIS package funds on functional support services simply because they are deemed by the NDIA to be palliative, or because their functional needs have changed as a result of the progression of their life-limiting illness.

The NDIA must ensure that potential NDIS participants do not have access rejected on the basis of shortened life expectancy. Nor should current participants have supports reduced due to palliative diagnosis. In some cases, supports will need to increase in line with the trajectory of the disability through end of life.

Prior to changes made to NDIA processes in 2023 (in response to a greater number of people under 65 being diverted from residential aged care), people with a short life expectancy were indeed gaining access to the NDIS, as long as they met access requirements regarding their disability. Establishing rapid access packages would help reverse some of the unintended consequences resulting from recent changes to NDIA processes, including inequities in access to support for this vulnerable cohort compared to people with other disabilities.

It is proposed that the NDIS funds rapid access packages for this cohort for a period of 3 months, with automatic rollover. As with any other NDIS participant, packages would be funded for supports deemed reasonable and necessary. Unlike other NDIS participants, recipients would not be asked to go through a protracted planning process with respect to their individual goals, but instead be given supports with the objective of allowing them to remain at home and to live as independently and safely as possible.

This immediate proposed service response would begin to resolve the crisis that has recently emerged for the group of people with disabilities associated with a life-limiting condition who have sought support from the NDIS. It would not however address the full gap in services for the cohort in question.

The program of support described below would be a medium-term solution and would address a broader range of support needs for this group.

2.2 An interim program of support



Recommendation

URGENT PRIORITY INVESTMENT 2024–25

The Australian Government should establish a new program of non-clinical care and support for people under 65 with a disability associated with a life-limiting illness, who need support with the activities of daily living to remain at home and out of hospital, and who cannot access this support through the NDIS or State/Territory-funded services. The program should be established on an interim basis for two years (or until a lasting solution has been found).

A program of funded support would be established for people with life-limiting illness who are ineligible for or unlikely to access the NDIS, and who cannot access aged care supports because they are under the age threshold, as well as NDIS participants whose life-limiting illness is not associated with their primary disability, and those who fall outside existing State/Territory funded programs and/or have exhausted all other available options. **The goal of the program would be to provide support to people with life-limiting illness who need assistance with daily living activities (see list below). This support would complement, but not duplicate, the clinical care available through the state and territory-funded palliative care system and other health services.** It would resemble the at-home support that people over 65 can access from the aged care system (support that is not currently available to those under 65), although children and young people may need quite different forms of functional support.

Eligibility would include people under 65^c who:

- a) Are NDIS participants diagnosed with life-limiting condition, where that condition is not associated with their 'primary' disability (i.e. the original reason why they need NDIS-funded support),^d or
- b) Are not NDIS participants^e and are diagnosed with a life-limiting condition.

In addition, eligible recipients would:

- a) Be enrolled as patients with a specialist palliative care service, or assessed by a medical practitioner as having unmet supportive and palliative care needs, and
- b) Have a life expectancy of 12 months or less, where the illness is associated with a functional disability leading to a need for support with daily living, and/or
- c) Regardless of life expectancy, be at risk of entering an institutional setting such as hospital or residential aged care in the absence of assistance with daily living, functional and other basic non-clinical support.

^c Or under 50, for Aboriginal and Torres Strait Islander people.

^d It is not intended that people with a primary diagnosis of a life-limiting condition on the NDIA's [List A](#) (conditions that are likely to meet the disability requirements) or [List B](#) (conditions that are likely to result in a permanent impairment) would need to access services from this program, because disability supports should continue to be available from the NDIS as their conditions deteriorate or their needs increase. The exception would be where these NDIS participants have a different and unrelated life-limiting condition.

^e It is not intended that intended recipients would need to test their NDIS eligibility as a condition of accessing services. This would not be consistent with the goal of facilitating rapid access to services.

PCA estimates that approximately 3,000 people would be eligible for the program each year, but with available data it is difficult to be precise about the level of unmet need.

Services available through the program, and included in PCA's costings, would include:

- ♥ Personal care assistance
- ♥ Domestic assistance/cleaning
- ♥ Transport
- ♥ Social support
- ♥ Respite
- ♥ Assessment of functional support needs (where an assessment by a specialist palliative care service is not possible).^f

Proposed program exemptions

There are a range of services that are critical to meeting the needs of this cohort, but which for practical reasons will be difficult to provide through an interim program of support. Therefore there are several specific program exemptions that are not included in PCA's costings. These specific proposed program exemptions include:

- ♥ Equipment^g
- ♥ Home modification
- ♥ Specialist disability accommodation (see further discussion below).

As with the system of at-home supports for aged care recipients, supports could be tiered depending on the level of disability, functional need, and access to informal and/or non-clinical support (though not tiered according to diagnosis or condition). The emphasis would be on facilitating access to support quickly through standardised, tiered packages (as with aged care) rather than a more extensive and individualised planning process (as with the NDIS). However, it is important to retain flexibility in the type and timing of services purchased through each package type so the program can be responsive to individual and changing needs. For example, the paediatric cohort (under 18 years) are likely to need a quite different set of supports compared with adults.

^f Assessment could be based on a standardised tool to support prognostication, such as the Supportive and Palliative Care Indicators Tool (SPiCT).

^g State/Territory Governments typically fund some equipment for patients, depending on circumstance. Available equipment may not include specialised or high-level equipment for people with specific disability needs, and State/Territory Governments commonly do not fund equipment for NDIS participants. This arrangement has become more challenging recently because State/Territory equipment services will not provide equipment to NDIS participants, while at the same time the NDIS will not provide equipment deemed to be associated with a palliative care need rather than a disability need.

"I want to be in my own place, to be with my own family, but I need help to be there."

Aboriginal mum, early 40s, in hospital separated from family.

"We felt completely unsupported and without options."

Young mum, caring for her husband.

"The NDIA ask for inappropriate levels of information because the patient is known to palliative care services."

Palliative care professional

Supported Accommodation

A small proportion of people with life-limiting illness may have more severe disabilities or functional needs, may in the past have been referred to/discharged into residential aged care (as the 'provider of last resort'), and may still be at risk of hospital admission for lack of safe alternatives. Some packages of support could be aimed at providing suitable accommodation in addition to the other support services described.

Some people in lower tiers of support might transition into supported accommodation as their function declines in the last months or weeks of life because they do not require, do not have access to, or simply prefer to stay outside of an inpatient palliative care unit. Conversely, some people's needs may become less pronounced in the short term – e.g. as someone in a specialist palliative care or acute hospital unit recovers from an episode of illness – but they still cannot be safely accommodated at home. In this sense, supported accommodation could reflect a 'step up, step down' model – where some people are referred 'up' from the home environment settings, and others are referred 'down' from inpatient services – reflecting the 'step up step down' model commonly used in other care and health settings.

There are complexities in determining the cost of supported accommodation and the breakdown between those people in this cohort who would need accommodation versus those who can be supported at home. For this reason, the costs of accommodation are not included in PCA's costings.

Neither supported accommodation nor home modifications are proposed as part of the interim program of support, and are not costed in this proposal. However it will be critical that these needs are met in any lasting arrangements agreed by jurisdictions about the services delivered

How would this program be delivered?

While there is a clear gap in services that needs to be filled, PCA is **not** calling for a whole new service system. The services in question could be provided by registered NDIS providers or aged care providers, with all the safeguards on offer through those systems.



Recommendation

To facilitate the program – to link people in need with the right services in timely fashion – the Australian Government should consider funding a grant, through which an NGO could work with the palliative care sector to commission support services from suitable providers.

PCA is prepared to assist in meeting this identified urgent service gap, by working with the palliative care sector to commission support services from suitable providers. In undertaking this work PCA would draw on the advice of its state and territory member organisations and established relationships with service providers. Under this model PCA would manage the grant, in partnership with its national network, negotiating service arrangements with registered providers via brokerage arrangements. Providers would be registered providers of NDIS or aged care services, with the relevant quality assurance, complaints escalation and accreditation standards in place.^h

"Her two children were aged in their mid-twenties. They moved in on a roster basis to supplement the private carer they had hired to stay with her for several hours during the day. As young people, they found it traumatising seeing their mother ill."

Palliative care professional

A key benefit in proceeding in this way is the ability of suitable local organisations to also support recipients to undertake advance care planning that reflects their end-of-life wishes – which in turn can help reduce avoidable hospitalisations and ED presentations. In addition, PCA and its member network have strong stakeholder relationships with organisations already delivering equivalent services, such as agencies delivering in-home aged care.

A grant of this nature should be funded for two years, with a lead in time of six months. An evaluation of this approach would provide key data to develop a more lasting solution by governments. PCA would be happy to discuss how this might work in practice with the Department of Health and Aged Care.

How much?

Because the population eligible for the program is relatively small (**approximately 3,000 people per year**), the costs of services would be modest: **by PCA's estimate, \$38.4 million per year, or \$77.6 million over financial three years**, which allows for a 6 month set up period and two years of funded services.ⁱ

The alternative – long-stay hospital admissions due to an absence of at-home support – would be much more expensive for governments and not at all consistent with quality care.

Who would pay?

PCA is firmly of the view that services should be made available to those in need as swiftly as possible. Decisions about which system pays should be a matter for governments to sort out behind the scenes without delaying provision of care or impacting the health and wellbeing of people with serious conditions or relying entirely on informal carer support.

Noting the ongoing uncertainty regarding jurisdictional responsibility for the services in question and regional variation in services available for this cohort, as well as the urgency in meeting the gap in services for this vulnerable group, it is proposed that the Australian Government cover the costs for this interim program.

^h The model of a non-government organisation negotiating support services in the health field is not new. Current grants are provided to McGrath Foundation for breast care nurses, to Canteen for acute oncology services for young people, to AbilityFirst to coordinate support for young people at risk of entering residential aged care, and to Diabetes Australia for the National Diabetes Services Scheme.

ⁱ Detailed year on year costings are available on request.

More lasting cost-sharing arrangements would then be negotiated between Commonwealth and State/Territory Governments once system interface boundaries are clarified, perhaps through the National Health Reform Agreement. This is discussed further at Section 5.4.

PCA notes that some states have programs in place which overlap to some extent with the proposed program.^j In some cases services are provided for a given period (e.g. six weeks), or restricted to people whose life expectancy is very limited. Some services are supported by donations rather than government funded. In addition, access to those programs depends on location; it can be harder for people in regional areas to access services, even if they are notionally eligible. PCA envisages that the proposed program would be managed to exhaust any locally available services before funding any additional support services.^k The Australian Government could also consider recovering costs from States/Territories after services are provided, particularly for services in jurisdictions where the services in question are not funded.

2.3 Longer-term solutions



Recommendation

Governments should provide a clear resolution of the respective roles of different tiers of government and different portfolios regarding responsibility for the delivery of non-clinical support services for people under 65 with life-limiting conditions. This should occur both through the National Health Reform Agreement and, as recommended by the Independent Review of the NDIS, a new system of 'foundational disability supports', including 'state and territory home and community care support programs to provide additional support to people with disability outside the NDIS'.

The Independent Review of the NDIS provides a roadmap to address essential and persistent interface challenges. Recommendation 1 is to “Invest in foundational supports to bring fairness, balance and sustainability to the ecosystem supporting people with disability”, with Action 1.8 that “National Cabinet should agree to jointly invest in state and territory home and community care support programs to provide additional support to people with disability outside the NDIS.” PCA strongly supports these recommendations.

^j These include the Queensland Community Support Scheme, End of Life Packages in NSW and the Victorian Home and Community Care (HACC) Scheme in Victoria. Some of these programs require that applicants test their NDIS eligibility to access funded services. While it is intended that recipients of the proposed program exhaust any entitlements/access under state/territory-funded programs, doing so should not involve testing their NDIS eligibility – which is not appropriate for the cohort in question and would be counterproductive in rapidly facilitating access to services for people with limited life expectancy.

^k It is not envisaged that recipients would need to test their NDIS eligibility to access the program. This is a feature of some State/Territory programs which is not well-suited to people with limited life expectancy.

A central recommendation of the Independent Review of the NDIS:

The Department of Social Services (DSS) with states and territories should develop a multilateral schedule to a new Disability Intergovernmental Agreement (see Action 20.1). The multilateral schedule should:

- Strengthen existing APTOS principles and detail shared responsibilities for the provision of concurrent supports. This will include accountability for meeting regulatory obligations in shared delivery situations (such as joint clinical governance)
- Clarify existing responsibilities that are disputed or ambiguous and add new responsibilities where gaps exist
- Facilitate significant updates for key interface areas including justice (including forensic issues), health (including palliative care), early childhood development and school education

The Review highlighted the interface between the palliative care and disability systems as one of several areas where “the problems remain significant” and “challenges... remain unresolved”. The Review also recommends the development of “a multilateral schedule to a new Disability Intergovernmental Agreement,” which would “facilitate significant updates for key interface areas... including palliative care”.²⁷

For this work to proceed on a solid foundation we need to better understand the system of services that currently do and do not exist for people with life-limiting illness in different parts of Australia. There is a significant variation between jurisdictions, even between and within regions, and between regional and metropolitan areas, regarding the services currently available from palliative care services and the health system for people with life-limiting illness. This variation complicates the task of identifying which services are available for the cohort in question, and which system(s) have responsibility for their delivery.

PCA proposes the government commission research to identify, in collaboration with key stakeholders, how service gaps could be addressed through different systems by adopting models of best practice and improved streamlining of systems and pathways. This work would identify the scope of services required to appropriately support people with life-limiting illness with different levels of need and at different stages of their illness trajectories and apply a systems lens in determining how critical service gaps can be addressed.

In addition, work should be undertaken to model the economic costs and benefits of the current and anticipated future range of services in keeping this cohort at home where possible. Finally, an evaluation should be commissioned of the interim program of support proposed above to identify lessons for future policy and program design.

The information gathered through this exercise would then inform the development of a draft framework for which systems could/should provide which services, and in what circumstances. This framework would then be considered by government as the basis for a lasting solution, clarifying the respective roles of palliative care and mainstream health, aged care, the NDIS, and other systems. As recommended by the Independent NDIS Review, this could be through the a multilateral schedule to a new Disability Intergovernmental Agreement. The current Mid-Term Review of the National Health Reform Agreement provides another mechanism for clarifying roles and responsibilities for different services that people under 65 with life-limiting illness may require from various systems.

Governance and next steps

Responsibility for these services is shared between the Commonwealth and States/Territories. However, we strongly urge government to involve experts, stakeholders and people with lived experience in the design of any solutions. This will ensure that the solutions identified for government consideration will address genuine need and are well-targeted and sustainable.

PCA recommends bringing together a group of stakeholders to discuss this draft proposal and reach consensus on governance. PCA would be very happy to work with the Department of Health and Aged Care and The Department of Social Services to convene this important gathering.

"It leaves patients and families absolutely distressed and distraught."

Palliative care professional.



Recommendation

The Australian Government should commission research to map non-clinical support services currently available through different systems for people under 65 with life-limiting conditions, and to identify gaps in services that support people to remain at home and out of hospital.

2.4 Realigning the NDIA's approach to life-limiting conditions



Recommendation

NDIA should convene a time-limited advisory group to provide advice to the NDIA on how its existing approaches to the assessment of access requests and to planning can be adapted to better meet the needs of people with life-limiting conditions.

In addition to the program proposed above (available to people who cannot get the right support from the NDIS), clarification of interface boundaries, and inclusion of palliative care in State/Territory-funded home and community care services, there is also need for substantial change in the NDIA's approach to people with life-limiting conditions. As with the broader Australian population, most NDIS participants will ultimately die from a life-limiting condition, and they deserve the same level of timely access to non-clinical supports (to complement any clinical care) as any other Australian.

The NDIS is built around the needs of people with disability who may need support for decades. The process of building a funded plan is simply not fit for purpose for people with a short life expectancy, who may often miss out on the services they need because they die while they await a decision by the NDIA.

People under 65 with life-limiting conditions are not necessarily approaching the NDIS by choice. Unfortunately, for some people under 65 with life-limiting conditions, the NDIS represents the only prospect of getting the functional support that they need. The process of assessing eligibility and if eligible, preparing a funded plan is time-consuming at a time when people have little time left to live. It can be administratively burdensome, requiring the support of advocacy organisations, and is often traumatic for the individuals involved, their carers, and families. It is especially troubling when there are children involved.

PCA has heard multiple accounts of the NDIA enquiring of parents how long their child is expected to live, with the direct implication being that if life expectancy is less than 12 months then services will be withdrawn.

"For ethical reasons, it is important not to harm patients approaching the end of life by providing burdensome investigations... that can be of no benefit."

Australian Commission on Safety and Quality in Health Care, *National Consensus Statement: essential elements for safe and high-quality end-of-life care*

"The NDIA appears to take the view that a participant's disability is the specific diagnosis or impairment that access to the NDIS was granted for. This is confusing for participants with multiple disabilities who justifiably understand their needs more holistically and expect the same from the NDIS."

Those limitations become even more confusing where the NDIA does not provide clear explanations for decisions it takes. Often the NDIA relies on legalistic language, broad references to elements of the legislation and its own obscure planning terminology. These communication and language barriers are commonplace. They create significant frustration for participants and erode trust in the NDIS."

Independent Review of the NDIS

"It's held over the family's head if they are known to paediatric palliative care services."

Palliative care professional

Where someone has an unfortunate experience with the NDIS, they can of course seek a review through established channels. However, there are limits to what can be achieved by reviewing individual cases. Fundamental changes are also needed at the systemic level. PCA proposes that the **NDIA convene a time-limited advisory group**, with appropriate expert and stakeholder representation, to provide advice to the NDIA on:

- ♥ As a first priority, establishing rapid access 3 month package of at-home support (with automatic rollover) for people whose life expectancy is less than 12 months, and who would otherwise be able to access the NDIS (as proposed in Section 2.1 above).
- ♥ How its approaches to the assessment of access requests and to planning can be adapted to better meet the needs of people with life-limiting illness, taking into account:
 - The realities of the existing palliative care service system, including widespread service gaps, rationing and thin markets.
 - The need for functional support at different stages right up to the end of life
 - The inherent uncertainty in predicting life expectancy
 - The distinctive needs of participants of different ages (and their families), including infants, children, young people, and adults.
- ♥ Establishing a centralised and consistent system for making rapid and transparent determinations regarding eligibility for and referral to different service types for people with life-limiting illness and/or people whose life expectancy is unclear (under the principle that sorting out who pays should be a matter for governments to sort out behind the scenes, and not the responsibility of individuals with serious health conditions or their carers).
- ♥ Input into the response to the Independent NDIS Review's recommendation for a multilateral schedule to a new Disability Intergovernmental Agreement, which should "clarify existing responsibilities that are disputed or ambiguous and add new responsibilities where gaps exist" and "facilitate significant updates for key interface areas including... palliative care".

In addition, PCA proposes the NDIA leverage existing Australian Government investment in education and training programs to build knowledge and understanding of the palliative care system and palliative care concepts among NDIA assessors, planners, and relevant contractors.



Recommendation

The NDIA should provide palliative care training for assessors and planners. This should leverage existing Australian Government investments in workforce palliative care training.

"The last six to twelve months has just been stonewalling by the NDIS."

Palliative care professional

3.0 Palliative care at home for people over 65



Recommendation

PCA recommends that the Australian Government's new in-home aged care program:

- ♥ Establish a new stream for palliative care with funds attached, to prioritise rapid access to care at home for people who have very significant palliative care needs.
- ♥ Not limit eligibility for a palliative care stream to people with very low functional capacity (AKPS40 or lower).¹
- ♥ Ensure people can access palliative care at home during the anticipated last year of life, as a minimum.
- ♥ Be designed to respond to changing needs, including episodic requirements for higher support.
- ♥ Ensure access to palliative care is included by design across all tiers of in-home support.
- ♥ Require workforce training in palliative care including for personal care workers, and ensure this training is adapted for people from a range of culturally and linguistically diverse backgrounds.
- ♥ Provide for respite care, both in-home respite and centre-based/overnight care for those with palliative care needs.

The Royal Commission into Aged Care Quality and Safety argued that palliative care should be core business in aged care. Current reforms are starting to make this a reality in residential aged care, but we also need to make sure that palliative care is accessible for people receiving aged care at home.

PCA strongly supports the Department of Health and Aged Care's intention to create a new stream for palliative care as part of the new Support at Home Program, which is expected to commence from 1 July 2025. We note this would address Recommendation 118 of the Royal Commission into Aged Care Quality and Safety:

The Australian Government should pay subsidies for service provision within the **care at home category**... [that] provide an entitlement to care based on assessed need across... domains including... palliative and end of life care.

¹ The Australia-modified Karnofsky Performance Status (AKPS) is a measure of the patient's overall performance status. A score of 40 or lower indicates a person who is in bed more than 50 per cent of the time.

PCA understands the Government is considering using the same cut-off determining eligibility for the fifth tier for palliative care that applies to the Australian National Aged Care Classification (AN-ACC) Class 1 (for palliative care): a life expectancy of three months or less, and a AKPS score of 40 or below.²⁸ PCA recognises the value of prioritising access for people who have an assessed life expectancy of three months or less, and who have significant palliative care needs.

PCA cautions against restricting access to a new fifth tier to only people who have an AKPS score of under 40, which would unduly limit eligibility to people with very low levels of function. Different illnesses have very different trajectories with respect to the level of functioning over time. We therefore suggest raising this threshold to a higher AKPS score or using a different approach.

More broadly, PCA urges the Australian Government to ensure the new Support at Home Program enables priority access to at-home aged care services across all other tiers of support (Tiers one to four), at a minimum for people with an anticipated life expectancy of 12 months or less. This timeframe reflects the Australian Commission on Safety and Quality in Health Care (ACSQHC)'s understanding that "people are 'approaching the end of life' when they are likely to die within the next 12 months."²⁹ Early learning from the implementation of AN-ACC Class 1 (palliative care) in residential aged care also indicates the challenges of determining palliative care eligibility based on restrictive timeframes and functional criteria. These issues are described in more detail in the next section.

In addition to these matters of eligibility, PCA notes that the success of the Support at Home Program will rely on:

- ♥ Home care packages (including the fifth tier for palliative care) that are sufficiently flexible to respond to changing needs, noting that some people will need more support on an episodic basis – in addition to expected decline over the progression of a life-limiting condition, including sudden decline.
- ♥ Design of the first four tiers to facilitate palliative care and other support services at lower levels of intensity – noting that many people receiving aged care services at different levels will likely have a life-limiting condition of some kind.
- ♥ Inclusion of provision for respite care, both in-home respite and centre-based/overnight care, for those with palliative care needs and their carers.

Given current well-known aged care system challenges and capacity constraints, full integration of palliative care within Support at Home will require a new level of coordination between aged care, specialist palliative care and primary care services. This direction is consistent with the recommendations of the Royal Commission into Aged Care Quality and Safety.

The success of the Support at Home program will depend on provider and workforce readiness to offer enhanced services. Workforce training is one essential component of the resourcing required to support this shift. PCA recommends that existing programs supported by the Australian Government to build palliative care capability in the aged care workforce be made available to the in-home aged care workforce, including personal care workers. This must include adapting this training for people from a range of culturally and linguistically diverse backgrounds, covering basic competency in death, dying and palliative care concepts to be mandatory. Such training could be accessed via the End of Life Directions in Aged Care (ELDAC) initiative.

Further recommendations regarding the Primary Health Network-led Greater Choice for At Home Palliative Care initiative, emphasising integrated aged and primary care, are detailed under 'Primary Care.'

4.0 other Commonwealth responsibilities

4.1 Residential aged care

PCA congratulates the Australian Government and aged care providers on what has been achieved to date in response to the Royal Commission on Aged Care Quality and Safety's findings and the subsequent rollout of aged care reforms. Building on these changes, PCA makes several recommendations to further secure the central place of palliative care in aged care.



Recommendation

The Department of Health and Aged Care should require that all aged care residents receive a palliative care assessment upon entry into residential aged care facilities. Further, if a resident is classified as palliative, this status should be retained for the duration of that person's care, and appropriate palliative care planning provided.

Most importantly, we recommend that all aged care residents receive a palliative care assessment upon entry. This should ideally occur both through meaningful inclusion of palliative care needs in the new Integrated Assessment Tool currently under development to assess eligibility for all aged care services, and an additional assessment of care needs on entry to residential care. The latter is consistent with the expectations set out in the pilot Strengthened Quality Standards, which require all residential aged care providers to assess (and regularly reassess as circumstances change) consumers' needs, goals and preferences including in relation to advance care planning and end of life planning.³⁰

Almost all residents entering an aged care facility will have one or more life-limiting condition, and almost all will die either in the facility or in hospital while a resident. This does not mean that everyone with a life-limiting condition should attract the same subsidy as those with the highest care needs, but instead that every resident's needs are given due attention as they change over time.



In addition, there should be a re-appraisal of the parameters for AN-ACC Class 1 (palliative care), which was originally intended to apply only to residents entering residential aged care for the purposes of receiving palliative care during their final weeks or months. However, the need for palliative care among aged care residents is much broader: Class 1 does not include (and therefore providers are not necessarily appropriately compensated for meeting the needs of) the following groups:

- ♥ New and existing residents who become palliative after entry to residential aged care, which would constitute most people who die in aged care, but for whom no equivalent to Class 1 exists.
- ♥ People who are palliative upon entry but whose life expectancy is longer than three months, or who have an AKPS score of above 40 (i.e. those who are not bed-bound).
- ♥ People who are palliative but have not submitted a completed Palliative Care Status form within 14 days of entry (noting confusion among aged care providers and health services about who/which system is responsible for completing this form).

There are inherent problems in the AN-ACC Class 1's restrictive life expectancy eligibility criteria.

- ♥ Limiting eligibility to people with an assessed life expectancy of three months or less is inconsistent with the ACSQHC's definition of 12 months as the timeframe in which 'people are "approaching the end of life" – this is described by the ACSQHC as the 'medium term'; the 'short term' is when someone is likely to die 'within days to weeks'.³¹
- ♥ Estimating life expectancy is an inherently inexact science, and these uncertainties can make doctors reluctant to draw definitive conclusions about short timeframes – meaning people whose prognosis is uncertain may miss out on the services they need.
- ♥ Accessing palliative care earlier than three months has been shown to save money, not increase cost. This is because earlier referral and advance care planning can reduce hospitalisations that are potentially avoidable. Extending the timeframe to access palliative care will therefore not necessarily translate into increased service costs.

The Australian Commission on Safety and Quality in Health Care describes end of life care as "care that includes physical, spiritual and psychosocial assessment, and care and treatment delivered by health professionals and ancillary staff. It also includes support of families and carers, and care of the patient's body after their death. People are 'approaching the end of life' when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with:

- ♥ advanced, progressive, incurable conditions.
- ♥ general frailty and co-existing conditions that mean that they are expected to die within 12 months.
- ♥ existing conditions, if they are at risk of dying from a sudden acute crisis in their condition.
- ♥ life-threatening acute conditions caused by sudden catastrophic events".³²

With these issues in mind, PCA believes there should be a re-examination of the applicability and usefulness of Class 1 in reflecting the full costs of care of those in residential aged care who are palliative (using a broader definition, such as the ACSQHC definition cited above), and ultimately in driving quality care. If the current structure of AN-ACC is retained, then at the very least there needs to be other mechanisms to flag and respond rapidly to the needs of palliative residents, and to remunerate providers appropriately. PCA also highlights the importance of regular public release of data about length of stay within aged care for people who enter residential aged care under all AN-ACC classes.

Further recommendations on residential aged care are made below in relation to the Comprehensive Palliative Care in Aged Care measure.



Recommendation

The Department of Health and Aged Care should re-evaluate the applicability and usefulness of AN-ACC Class 1 (Palliative Care) in reflecting the full costs of care of those in residential aged care who are palliative. While this work occurs, a broader definition of 'palliative' should apply for any services available through the new At Home Support Program.

The Royal Commission into Aged Care Quality and Safety emphasised that palliative care can only be fully integrated as core business in aged care when the workforce is trained, skilled and supported to build capacity in this area. The Royal Commission recommended compulsory training in palliative care and dementia for everyone working in aged care.³³

PCA recognises the efforts of the Australian Government and agencies in this area. To maintain the necessary pace of change in this vital area, PCA is seeking Australian Government funding to enable aged care services to ensure Registered Nurses (RNs), who play an essential clinical and staff leadership role in residential aged care, have palliative care skills and knowledge. This includes providing funds to backfill nurse positions while they undertake training, and travel costs for those in remote areas to undertake placements. This should be provided through evidence-based programs already funded by the Australian Government, for example the Program of Experience in the Palliative Approach (PEPA) and Reverse PEPA Placements, where palliative care specialists can be placed in residential aged care settings.



Recommendation

PCA seeks Australian Government investment of \$20.1 m over three years in palliative care training for Registered Nurses (RNs) working in aged care, including backfilling, and travel costs for those working in remote areas to undertake placements.

Further recommendations on residential aged care are made below in relation to the Comprehensive Palliative Care in Aged Care measure.

4.2 Primary care

PCA welcomed the reforms announced in primary care in the May 2023 Federal Budget. These reforms provide an efficient and sustainable funding approach to increase access to palliative care for Australians requiring palliative care who remain in their home or reside in aged care. Further, these reforms can assist those with complex needs to remain at home, in coordination with specialist palliative care services. Efficiencies in the health system can be achieved through reduced emergency department visits and reduced hospital admissions.³⁴



Recommendation

To take advantage of the opportunities of MyMedicare to improve access to palliative care, PCA recommends:

- ♥ **A palliative care assessment for MyMedicare-enrolled patients as standard practice and, where an unmet need for palliative care is found, a coordinated plan for the provision of palliative care should be put in place by the practice.**
- ♥ **Funding for coordination of a palliative care plan should be recognised in the funding provided to a practice through MyMedicare.**
- ♥ **Basic training in palliative care for all GPs and practice nurses as a requirement for practices participating in the MyMedicare program. Training is available through existing Commonwealth infrastructure such as the PEPA. Funding could also support MyMedicare-registered practices to invest in education and training for other health professionals in the practice to provide palliative care within their scope of practice – for example Occupational Therapists who can assess the functional supports needed to assist a person remain at home. There are a range of existing educational resources and initiatives funded by the Australian Government that can support such education and training.**
- ♥ **Pending the outcomes of the current Scope of Practice Review, support practice nurses in primary care to work at the top of their scope to provide palliative care to patients in the community and in aged care services, and to engage in discussions with patients about end-of-life care and advance care planning.**

The Primary Health Network-led Greater Choice for At Home Palliative Care initiative is intended to better coordinate access to palliative care in home and community settings (including in aged care), but it does not provide any additional system capacity. It is unclear whether the Greater Choice initiative has the system leverage to deliver the anticipated improvements in system integration. The sector would welcome further information on the measurable impact of the Greater Choices initiative on access to quality palliative care for critical population groups, including people receiving residential and at-home aged care.

4.3 Sector capacity



Recommendation

PCA recommends the Australian Government undertake a review of the guidelines for the Health Peak and Advisory Bodies (HPAB) Program.

Until July 2023, PCA received core peak funding under the Health Peak and Advisory Bodies (HPAB) Grants Program. In 2022, the guidelines for the HPAB program were revised to reflect the objectives of the National Preventive Health Strategy. PCA was subsequently unsuccessful in its application for renewed HPAB Program funding, with 18 other peak bodies also losing access to this funding stream.

PCA fully supports the need for action in preventive health. However, many areas of health and health reform fall outside the remit of the National Preventive Health Strategy but remain no less crucial as a result to the health and wellbeing of the Australian population. It is difficult to understand the Australian Government's policy rationale for removing its support for peak bodies, including but not limited to palliative care, in such a way. As a result of the recent changes in the HPAB Program guidelines, the scope and quality of advice to the Australian Government on these areas is curtailed.

PCA therefore strongly recommends the Australian Government review the guidelines for the HPAB Program before any future funding decisions under this program are made.

4.4 Cancer care



Recommendation

PCA encourages the Australian Government to work with partners to ensure palliative care is fully integrated into the new Australian Cancer Nursing and Navigation Program, including in outcomes measures, particularly within the new national all-cancer nursing service.

PCA welcomes the November 2023 announcement of the Australian Government's Cancer Nursing and Navigation Program, which comprises a new national all-cancer nurse service, along with:

- ♥ A multidisciplinary telehealth cancer navigation service
- ♥ A Child and Youth Cancer Hub which will deliver cancer navigation, support and counselling for children and young people and their families, and
- ♥ A specialist telehealth service for people with particular tumour types.

PCA recognises that this is a significant investment in cancer services.

PCA particularly welcomes the establishment of the all-cancer nursing service. This extension of existing cancer nursing programs established and led by the McGrath Foundation, to an all-cancer model, has potential to support improved cancer care experiences and outcomes and contribute to more equitable access to best practice cancer care.

While short and long-term outcomes for many cancers continue to improve, cancers remain among the most common life-limiting conditions affecting Australians and among the leading causes of death. Over the decade to 2021, lung cancer and prostate cancers were among the ten leading causes of death for all Australia men; while lung cancer, breast cancer and colorectal cancer were among the leading ten causes of death for women.³⁵ Certain cancers, including lung cancer and trachea cancer, disproportionately affect Aboriginal and Torres Strait Islander people.³⁶ Less common and rare cancers include many with less clear clinical pathways, and lower survival rates when compared to all cancers.³⁷

Integration of palliative care in cancer care is critical to the successful delivery of holistic and effective cancer nursing models.³⁸ This requires:

- ♥ Clarity about the role of the cancer nurse and nursing team in relation to palliative care
- ♥ Provision of advanced care planning services
- ♥ Early information about and timely referral to palliative care
- ♥ Access to high quality palliative care including at end of life, and
- ♥ Access to bereavement services.

PCA therefore emphasises the importance of integrating palliative care within the all-cancer nurse service and within the full suite of services to be established under the Cancer Nursing and Navigation Program. This should include early work to establish clear outcome indicators, and a monitoring and evaluation framework, to determine the extent to which palliative care is embedded in the program.

5.0 Joint Commonwealth/State responsibilities

5.1 Comprehensive Palliative Care in Aged Care measure



Recommendation

URGENT PRIORITY INVESTMENT 2024-25

Palliative Care Australia and its members request the Australian Government continue funding the Comprehensive Palliative Care in Aged Care measure beyond June 2024. This would represent at least \$33 million investment by the Australian Government over three years to match current funding levels, with funding matched by states and territories.

PCA recommends the Australian Government draw on the recent evaluation of the Comprehensive Palliative Care in Aged Care Measure to develop key performance measures for the future National Health Reform Agreement to ensure that funding for palliative care in aged care is ongoing and there is accountability across both levels of government.

The Comprehensive Palliative Care in Aged Care Measure (CPCiAC) provides \$57.2 million over six years from 2018/19, cost-shared between the State/Territory and the Australian Governments and with completion due in June 2024. The palliative care sector supports this initiative, and ultimately, we hope that successful elements from CPIAC will be permanently embedded in our aged care and adjacent systems.

The mid-term report from the national evaluation of CPCiAC by the Nous Group indicates early success in achieving the aims of improving access to, and coordination of, palliative care for residents in residential aged care. There are signs that States and Territories are developing joined-up approaches at the interface of health and aged care. The matched funding arrangement has strengthened shared responsibility for addressing an area of significant need and supported the expansion of palliative care services in all States and Territories. CPIAC has facilitated both the expansion of existing models of care and enabled new approaches to the way palliative care, including specialist palliative care, is delivered outside of hospital settings and in residential aged care.

However, there are systemic factors that have limited progress in integration between the health and aged care systems. These factors include funding, governance, workforce shortages, GP and nurse remuneration, capability of personal care workers, and a lack of integrated care pathways. Further investment to extend CPCiAC should identify outcomes that link to systemic and lasting system changes.

It is clear there is a need for a further round of the CPCiAC measure (or a measure with similar goals). There were significant delays to implementation after funding was announced, such as the COVID-19 pandemic. It has been challenging for some states and territories to adopt a partnership approach and the time-limited funding limited what some jurisdictions chose to invest in. A lack of specificity on required data collection and sharing from states makes understanding the national impact of CPCiAC more challenging.

PCA and its members encourage the Australian Government to continue funding CPCiAC beyond June 2024, matching current State and Territory government contributions. In addition, governments should draw on the recent evaluation of CPIAC to develop key performance measures for the future National Health Reform Strategy so that there is ongoing, combined funding, and accountability by both levels of government to ensure palliative care is provided to all Australians in residential aged care services.

Given the critical role of primary care in aged care, there is a specific opportunity to identify lessons learnt from CPCiAC regarding how to encourage GPs to provide palliative care in residential aged care, including through on-site visits.



Recommendation

PCA encourages government to identify lessons from CPCiAC in relation to involving GPs in palliative care provision in aged care, and apply this learning to broader primary care reforms, including the implementation of MyMedicare.

5.2 National Palliative Care Strategy Implementation Plan



Recommendation

The Australian and State/Territory Governments should re-establish a high-level governance structure to oversee work under a refreshed National Palliative Care Strategy Implementation Plan, including critical data development work.

The National Palliative Care Strategy (2018) sets the shared commitment of Australian governments to ensuring the highest possible level of palliative care is available to all people. The Implementation Plan sets out agreed actions under the Strategy and is due to lapse in August 2024. Unanticipated changes have impacted on implementation of the National Strategy in recent years, including:

- ♥ The COVID-19 pandemic, during which established governance structures for monitoring and annual reporting against the Implementation Plan ceased.
- ♥ The Royal Commission into Aged Care Quality and Safety and subsequent major reforms to aged care, including initiatives aimed at embedding palliative care in aged care.
- ♥ Workforce challenges across the health system, which have also affected palliative care and placed strain on service provision.
- ♥ Recent primary care reforms, which create new opportunities to improve access to palliative care in primary and community settings.

These changed circumstances must be reflected in a refreshed Implementation Plan, along with the following future priorities:

- ♥ Restitution of a governance structure for the National Strategy and Implementation Plan, including oversight over ongoing work to develop quality data and evidence in line with the National Palliative Care and End-of-Life Care Information Priorities Document, developed by AIHW with broad stakeholder input.
- ♥ Commitment to transparent regular public reporting regarding Commonwealth and State/Territory investment in and provision of specialist palliative care.
- ♥ A focus on access to home- and community-based palliative care, including access to after-hours palliative care (see below).
- ♥ Implementation of the Paediatric Palliative Care National Action Plan, released publicly in July 2023. The National Action Plan is a roadmap for a national approach to prioritise and work towards common goals and objectives for paediatric palliative care.

5.3 After-Hours Palliative Care

After-Hours Specialist Palliative Care



Recommendation

URGENT PRIORITY INVESTMENT 2024-25

PCA calls on the Australian Government to invest in a gap analysis to identify national variability in access to after-hours palliative care and seek support from States and Territories to address gaps in after-hours access under a refreshed National Palliative Care Strategy Implementation Plan.

According to PCA's *National Palliative Care Service Development Guidelines*: 'after-hours care is considered accessible and effective care for people whose health condition cannot wait for treatment until regular care services are next available.' Unfortunately, access to after-hours palliative care is currently a post-code lottery. There is significant variability in specialist after-hours palliative care between and within jurisdictions. Lack of access to after-hours palliative care drives avoidable emergency hospital admissions, which are difficult for patients and families and costly and inefficient for the health system.

In addition to any commitments States and Territories may make in this area through a refreshed Implementation Plan, PCA recommends the Australian Government fund a gap analysis to identify variability in provision of specialist after-hours palliative care nationally, develop consensus benchmarks on access to high quality after-hours specialist palliative care, and identify opportunities for innovative service models that address unmet demand, prioritise high quality care, and ensure the safety of specialist palliative care professionals providing after-hours care

Improved access to after-hours palliative care could be supported through new primary care reforms including MyMedicare. Greater access to Nurse Practitioners and to practice nurses, particularly in rural and remote areas, and making full use of the scope of practice for nursing roles, would help support people receiving palliative care at home. As noted above (in relation to primary care), primary care reforms should require a palliative care assessment for patients enrolled in MyMedicare, and general practice should be supported financially to conduct home visits where necessary. This would assist patients with complex palliative care needs (in

consultation with a specialist service), those with less complex care needs who cannot travel, and people in areas where there is less access to specialist palliative care services.

After-hours pharmacy services



Recommendation

PCA calls for Australian Government investment of \$3.1m over three years to establish a national 'Palliative Care Aware' initiative for community pharmacy, to improve priority access to palliative medications and personal care supplies after-hours.

Building on the learnings of the Queensland Health "palliPHARM" pilot, this initiative will ensure priority access to palliative medications and personal care supplies for families in their toughest hours. 'Palliative Care Aware' pharmacists are trained and work alongside local prescribers to better anticipate out-of-hours needs for reduced unplanned hospitalisations. Working as a trusted support for the whole family this initiative enables local pharmacies to genuinely lift some of the carer burden so quality family time can be enjoyed. The initiative will also build capacity of residential aged care facilities to embed quality use of palliative medicines through investment in imprest systems.

- ♥ Pharmacy is in the top three most trusted professions in Australia.
- ♥ The average person visits a community pharmacy 18 times a year, in metropolitan, rural, and remote locations.³⁹
- ♥ Delivery services established and funded during COVID have ceased in a majority of services.

Through this initiative PCA will:

- ♥ Establish branding and patient information for in-store advertising of the service.
- ♥ Build GP and Pharmacist ability to identify and recognise palliative care patients and families by establishing a consistent national system to support this.
- ♥ Establish branding and patient information for in-store advertising of the service.
- ♥ Build GP and Pharmacist ability to identify and recognise palliative care patients and families by establishing a consistent national system to support this.
- ♥ Provide the baseline medications to be carried by each participating pharmacy, along with seed funding for each participating pharmacy for two years for:
 - Administration for medications (recognising the high administrative burden of dispensing some palliative care medications)
 - Establishing out-of-hours and priority delivery of medication for these patients.
 - Supporting flexible backfilling for pharmacists undertaking the PSA Foundation Training in Palliative Care
- ♥ Developing and providing guidance documents and templates for health professionals and pharmacists to introduce a collaborative, standardised and cross-jurisdictional approach to the issue of palliative care anticipatory medicines.
- ♥ List all community pharmacies that commit to the initiative, including holding palliative care medicines, on the National Palliative Care Service Directory.

- ♥ Targeted awareness campaigns to GPs, patients, specialist palliative care providers and other health providers about identifying *Palliative Care Aware Pharmacies*.
- ♥ Support all Residential Aged Care Facilities to embed appropriately stocked palliative care medicine imprest systems
- ♥ Provide Residential Aged Care Facilities nationally with flexible policy and procedure templates to support safe and effective management of palliative care medicine imprest systems.

This initiative would leverage existing investment in:

- ♥ PCA: Driving Quality: Palliative Care Australia's National Palliative Care Standards for All Health Professionals and Aged care Services and the National Service Directory.
- ♥ PSA: Foundation training for pharmacists in supporting palliative care – due for delivery by 2026 to increase palliative care anticipatory prescribing, stocking of medicines and easy, safe access to those medicines for timely administration if required.
- ♥ [caring@home](#): palliMEDS app for General Practitioners (GPs) – more than 6000 GPs are now using to assist prescribing.

5.4 National Health Reform Agreement

Through the National Health Reform Agreement (NHRA), governments should provide a clear resolution of the respective roles of different tiers of government and different portfolios regarding responsibility for the delivery of non-clinical support services for people under 65 with life-limiting conditions.

The Australian and State/Territory Governments should request that the Independent Health and Aged Care Pricing Authority (IHACPA) investigate how to build incentives for community-based palliative care into future pricing models, considering the financial savings associated with avoiding potentially preventable hospital admissions and ED presentations for people in their last year of life.

PCA supports the reforms introduced through the NHRA Addendum 2020–25 to improve health outcomes, efficiency and transparency in public hospitals and health services. However, current funding models can create perverse incentives that privilege essential but more costly inpatient care over palliative care delivered in the community. PCA sees significant opportunities for improvement in how our funding models are designed.

International studies have shown savings to hospital inpatient costs when palliative care is provided, including when it is provided early in a patient's hospital admission. Palliative care provided within the hospital setting, both in specialist units and across other acute wards, can reduce unnecessary admissions to hospital and presentations to emergency departments.

Given the potential for palliative care to reduce unwanted treatment and reduce hospital admissions and ED presentations, including in the last year of life, palliative care should be a natural area of focus for jurisdictions looking to manage public hospital costs without compromising quality, safety, or access to care. PCA suggests the following areas for further consideration as the NHRA arrangements are reviewed:

- ♥ Clear and final resolution of the respective roles of the Australian and State/Territory Governments and of health, disability, and other agencies, regarding responsibility for the delivery of non-clinical support services for people with life-limiting conditions and disabilities, in recognition of the essential role of these services in keeping people out of

hospital and living independently wherever possible. A key input would be the information gathering exercise proposed in Section 3.2 above in relation to non-clinical support at home for people under 65. This would investigate how service gaps could most effectively be addressed through different systems. The findings of this important work could then inform specific commitments made by different jurisdictions and portfolios under future iterations of the NHRA.

- ♥ Recognition of the key role palliative care can play in reducing avoidable hospitalisations and ED presentations, noting the high cost of (sometimes unnecessary) care delivered to people at end of life. This could be achieved through further work by the Independent Aged Care and Hospital Pricing Authority to quantify the benefits associated with potentially preventable hospitalisations associated with greater access to community-based palliative care, and to build these into future pricing models.
- ♥ Incentives for specialist palliative care services, via local hospital networks, to deliver palliative care:
 - To acute hospital beds in other parts of the hospital
 - In community-based settings
 - In collaboration with primary care and aged care services
 - Using innovative models of service delivery to improve access and outcomes.
- ♥ Block funding arrangements in rural and remote areas which better reflect the full costs of service delivery, including services delivered to palliative patients without the involvement of a palliative care physician.
- ♥ Monitoring and reporting on actual spending at LHD level on specialist palliative services, including community-based care, in addition to existing reporting arrangements which focus on the numbers of palliative care services delivered and hospital admissions.



Recommendation

Review of the NHRA should identify opportunities to incentivise, fund appropriately, monitor and report on community-based palliative care delivery at the Local Health District level.

5.5. Supporting the palliative care sector in the Northern Territory



Recommendation

PCA calls on the Australian Government to fund further work to improve access to quality palliative care for Aboriginal and Torres Strait Islander Australians, and to build the capacity of the palliative care sector in the Northern Territory. This should include shared Commonwealth/Northern Territory funding to support a peak body for the palliative care sector in the Northern Territory, at a total combined investment of \$900,000 over three years.

All Australian jurisdictions other than the Northern Territory have a funded peak state or territory organisation for palliative care. These organisations provide essential infrastructure for:

- ♥ Palliative care service planning and policy development.
- ♥ Sector and workforce development.
- ♥ Community engagement on matters including palliative care awareness, advance care planning education and promotion of services for families and carers.

The Northern Territory presents a uniquely challenging context for palliative care service provision due to its prevalence of geographically isolated regional and remote communities and high levels of complex disadvantage and unmet needs for health care, which particularly affect Aboriginal and Torres Strait Islander communities. The anticipated introduction of Voluntary Assisted Dying (VAD) adds to the complexity of the setting in which palliative care operates in the Northern Territory.

Aboriginal and Torres Strait Islander people in Northern Australia, as nationally, continue to experience significantly higher rates of chronic disease and life-limiting illness prevalence and death than the general population, particularly coronary heart disease, diabetes, respiratory illness, and cancers including of the lung, bronchus, and trachea.⁴⁰ Health and social inequities contribute to a life expectancy gap of nearly nine years for men, and eight years for women. This gap increases by a further six to seven years for people living in remote and very remote areas.⁴¹

The National Agreement on Closing the Gap sets the goal that Aboriginal and Torres Strait Islander people will enjoy long and healthy lives, with equitable access to health services by 2030.⁴² Access to palliative care is an essential aspect of health care and a component of the right to health. Yet in the Northern Territory, people living outside metropolitan and regional centres – primarily Darwin and Alice Springs – and especially those living in remote communities, have limited access to palliative care. People who travel to regional centres to receive palliative care too often die in hospital because it is not possible to return home. The cost to health services of avoidable hospitalisations is significant and the emotional toll on individuals and families immeasurable.

The requested Australian Government funding would provide a once-in-a-generation investment to identify need and to extend and consolidate access to culturally safe palliative care in the Northern Territory. Palliative Care Australia will work closely with Palliative Care Northern Territory to establish and support a sustainable peak palliative care organisation which will:

- ♥ Provide a central point for collaboration within the palliative care sector and with the wider health sector.
- ♥ Contribute to Northern Territory and national palliative care policy development.
- ♥ Provide leadership on end-of-life issues including in the context of the introduction of VAD in the NT.
- ♥ Provide a voice for consumers and carers.
- ♥ Engage with Aboriginal and Torres Strait Islander communities and organisations to improve access to culturally safe palliative care.

Palliative Care Australia and Palliative Care NT seek matched funding from the NT Government to support an initial three-year workplan focused on:

- ♥ Home and community end-of-life support.
- ♥ Adequate resources for specialist palliative care teams.
- ♥ Culturally safe holistic palliative care.
- ♥ Planning, service development and research in palliative care.

5.6 Improving access to palliative care for people who are homeless



Recommendation

PCA seeks Australian Government investment of \$500,000 over three years to provide palliative care education and training for 1,000 staff of specialist homelessness services, to build capacity to support and care for people living with a life-limiting illness while homeless.

People experiencing homelessness are some of the most disadvantaged in Australia. People who are homeless face intersecting physical, mental, and social burdens that greatly increase the incidence of illness, co-morbidities, and mortality relative to the general population. For people in unstable housing, the symptom management, treatment adherence and service access necessary for chronic and complex or life limiting conditions is extremely difficult. Palliative care is an essential component of the human right to health. Those dying in our streets or in insecure housing need tailored support to identify their needs and link them to available health services in the region.

- ♥ On Census night in 2021, over 122,000 people were estimated to be experiencing homelessness.
- ♥ One in seven people experiencing homelessness are aged 55 years and over.
- ♥ 20% of people experiencing homelessness identify as aboriginal and/or Torres Strait Islander people.⁴³
- ♥ With an ageing population and increased financial barriers/cost to renting and home ownership, this problem is set to get worse.

Under the proposal, PCA would manage a program of palliative care training for specialist homelessness services professionals, including program management and national monitoring and reporting. Training could be delivered by a network of PCA Member Organisations in each State and Territory. Scholarships to attend the training will be distributed relative to demand, based on the homeless population in each jurisdiction.

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