Palliative Care Australia

Palliative Care Australia's

2025 Federal Election Platform

Better access to palliative care
Worth voting for

Thank you for your interest in ‘better access to palliative care’ for all Australians who need it, wherever they are.

Adding her voice to the campaign is well-known actor, author, and comedian Jean Kittson. Jean has recently featured in ‘Mother & Son’ on ABC TV and iView but is well known as one of the funniest, most creative people in Australia through her work on TV and radio; shows like ‘The Big Gig’, ‘Good News Week’ and ‘Thank God it’s Friday’.

For the last 10 years she has been a carer for her mum and dad, Elaine and Roy, and wrote a best-seller about the experience ‘We Need to Talk About Mum & Dad – a practical guide to parenting aging parents.’

Jean has been a longtime advocate for palliative care and is the patron of Palliative Care Nurses Australia.

Sadly, Elaine (99 years) and Roy (96 years) died earlier this year, without the palliative care Jean expected to be able to access. She says she has been left with deep trauma and grief from the experience.

Jean is sharing her story publicly to raise awareness, so that other families have a better chance of accessing palliative care – when and where they need it.

You can watch and read Jean’s deeply emotional story on the Palliative Care Australia website.

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 our city and region.

Jean Kittson

actress, author, comedian, palliative care advocate

The growing crisis

Current data presents a confronting picture of access to palliative care now, and on our current path this will only get worse. Without action, our future is one of diminishing care for people and families living and dying with terminal illness.

Delayed access to specialist palliative care is a major issue. The average time someone receives specialist palliative care for the first time is just 15 days before death,[1] despite palliative care being important from the time of diagnosis of a life-limiting illness. Australia currently has only about half the number of specialist palliative care physicians our population needs[2], and the number of palliative care nurses – already much lower than needed – is growing well below the rate needed to keep up with population-driven demand.[3]

If Australia sees itself as a compassionate country, we cannot let this continue.

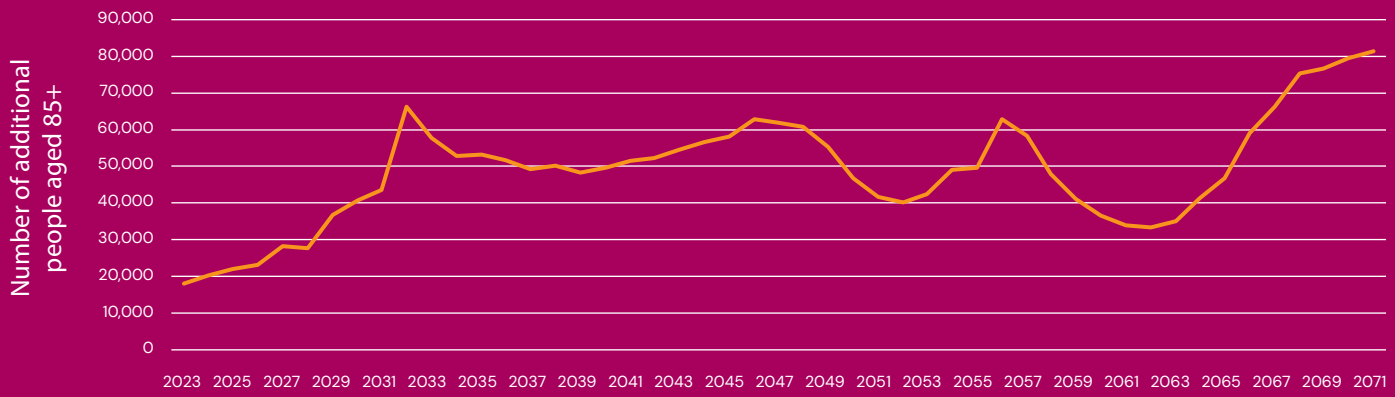
Palliative Care Australia's 2025 Federal Election Platform provides a blueprint for immediate actions the Australian Government can take, and our elected representatives can support, to improve access to palliative care.

Palliative Care Australia (PCA) and our members see this Platform as the next step in a long-term reform agenda to give Australians living with and dying from terminal illness a better chance at enjoying comfort, dignity and support in their final months and weeks.

Each day, around **400 people die** of a life-limiting illness[4].

Yet **more than three in five (62%) do not receive specialist palliative care** at any stage.[5]

Annual growth in the number of people aged 85+ in Australia[6]



What is the need?

What is PCA asking for? How much would it cost?

1. Better access to **palliative care in primary care**

Primary care is critical to meeting the growing demand for palliative care. Out of pocket costs should not be a barrier to receiving palliative care from your usual doctor.

- A new quarterly payment to primary care practices for each palliative patient to recognise the costs of delivering services not billable to Medicare: costing $61.5 million per year
- Supplement payments for home visits.
- Expert working group to provide further advice to government.
- Access to community-based palliative care actually saves money to government via lower rates of unnecessary hospital admissions and ED presentations.[13]

2. Better access to **critical palliative care medicines**

Australia's supply of critical pain relief medicines is under threat.

- 11-point plan endorsed by ANZSPM, AdPha, PSA, PCNA, Pain Australia and ACCPA.
- $14.8 million per year to abolish co-payments for medicines on the PBS Palliative Care Schedule.
- $10 million to fund a national stockpile of critical medicines where there is a supply risk.

3. Better access to **palliative care in aged care**

There is much more work to do to reach the Aged Care Royal Commission's vision that palliative care become "core business" in aged care.

- $32.8 million over 3 years to train 15,115 nurses providing 24/7 care in residential aged care and nurses working in home care.
- A new independent, two-yearly public report on palliative care in aged care.
- Address low uptake of the existing palliative care classification (AN-ACC Class 1) by basing funding on need, not prognosis.

4. Better access to **support at home for people under 65 with a terminal illness**

People under 65 don't have the same access to support at home as people over 65. This group of vulnerable Australians is falling through the gaps between the aged care system and the NDIS.

- $136.4 million over 3 years to establish an interim program of support to fill current service gaps.

1. Better access to palliative care in primary care

Delayed access to specialist palliative care is a major issue. Australia currently has only about half the number of specialist palliative care physicians our population needs,[14] and the number of palliative care nurses is growing well below the rate needed to keep up with population-driven demand.[15] Currently, people who are dying see a palliative care specialist for the first time just 15 days before death, on average.[16] **Three in five who die from a terminal illness (62%) don't receive any specialist palliative care at all.**[17]

Up to 90% of people say they want to be cared for at home with the appropriate supports, and at least half say they would prefer to die at home[18] – yet as few as one in twenty deaths actually happen at home.[19] More than 80% of deaths happen in hospitals and aged care facilities.[20]

Our existing primary care workforce, including General Practitioners, Practice Nurses and Nurse Practitioners, is key to turning that around. This is work the primary care sector can do, but only if the right incentives are in place.

This is good news for the community, and good news for government. If we empower the primary care sector to deliver more palliative care, we can achieve major savings to hospital and aged care budgets, and at the same time help realise the dying wishes of most Australians.

KPMG tells us that a $1 investment in community and home-based palliative care delivers a return of between 53 cents and $1.56 in savings to the health system.[21] In 2020-21 at least 8,915 people received potentially avoidable hospital treatment in their last year of life.[22] In the same year a typical overnight hospital admission cost $10,823.[23]

The majority of GPs see providing palliative care as part of their role. In fact, 39% say they are interested in doing more palliative care.[24] However, PCA's 2024 National Workforce Survey found only 11% of primary care workers agreed that their practice is adequately funded to deliver palliative care.

Palliative care is different from many other aspects of medicine. Consultations can be long, and the issues to work through are complex and challenging for all involved – consumers, carers and families, and clinicians.

End-of-Life Pathway for aged care recipients at home

A key recent development is the newly-announced End-of-Life Pathway under the aged care Support at Home Program. For the first time, people over 65 with a terminal diagnosis will be eligible for additional aged care services in their final months or weeks.[25] For people to remain at home, however, they will need ongoing access to clinical palliative care. State/territory-funded palliative care services can meet some, but by no means all, of this new demand, and care provided in hospital is often more expensive than care delivered in the community. **For the End-of-Life-Pathway to work as envisaged, we must also support primary care services to play their part.**

What consumers and carers say

"If your **local GP clinic** and **primary care nurses** could provide palliative care, **that would be invaluable** because at the moment it's like you can only get it when you're in hospital taking up a bed, and you may not want to be."

"It just it boggles the mind that in a place where most people are going to end up dying, that there's **not the right skills available to help** them do that in the best possible way."

What GPs say

In PCA's 2024 National Workforce Survey, the great majority of primary care workers agreed that *it is the responsibility of GPs to discuss palliative care with their patients* (81%), that *people should be able to access palliative care from the time of diagnosis of a life-limiting condition* (93%) and that *for people with life-limiting conditions, early discussion of palliative care is critical* (96%).

Most primary care respondents to PCA's survey (72%) said that in the past year they had experienced increased demand for palliative care, yet only 11% agreed that their practice was adequately funded to deliver palliative care.

Here are some of the things GPs told PCA in our recent survey:

"When I do get involved in palliative care it actually **costs me considerable income** to do so. Whilst I'm happy to do that for a small number of patients, **I cannot do it for many**."

"GPs who provide palliative care accept that they are **doing it out of compassion** and wish to assist the patients whilst taking a very low remuneration for this."

"It is unbelievable that certain areas of primary care have so many item numbers (skin removals for example) when the one area of care that will inevitably affect everyone, has none. **Medicare needs to start recognising the importance of primary care in palliative care** not by making more online platforms that no-one really understands, but by **funding it properly**."

What GPs said about their ability to conduct home visits

"Bulk billing home visits is **essentially uneconomic**."

"I may have to **reconsider home visits** if they aren't adequately remunerated."

Medicare and palliative care in General Practice

A succession of reviews and inquiries over the years have called for changes to the way primary care is funded to recognise its evolving role and changing patient needs. But despite ongoing reform, Medicare payments are not yet fit for purpose to promote high-quality palliative care. GPs generally bill responsibly, and in fact they can err on the side of under-billing for palliative care.

So PCA is calling for a new approach to fund palliative care properly, to make sure all people who need palliative care in primary care can access it. Cost should never be a barrier to receiving timely palliative care. Patients with a life expectancy of a year or less should be bulk-billed for their Medicare consultations, and GPs should not be forced to choose between billing a dying patient or receiving inadequate remuneration from Medicare.

Would practice payments be linked to MyMedicare?

MyMedicare is a new system of voluntary practice and patient enrolment to promote continuity of care. MyMedicare may in time help shift the primary care sector away from sole reliance on fee-for-service and toward blended payment models. While MyMedicare is a critical reform, PCA is calling for new payments which would not be linked to the MyMedicare status of patients in need of palliative care.

This approach recognises that many of a practice's palliative patients might be registered with another practice (if that practice does not specialise in palliative care, or wishes to refer to a practice with more expertise), and that some patients will have been recently referred following deterioration and perhaps a hospital stay.

Early evidence suggests that take-up of the new General Practice in Aged Care Incentive, which is linked to a patient's enrolled practice, is lower than it otherwise might be. With less than 10% of the Australian population yet enrolled with a primary care practice, PCA urges government to proceed with the proposals outlined without linking payments to a patient's MyMedicare status, and to await the MyMedicare system maturing further.

PCA's plan to improve access to palliative care in primary care

PCA is proposing a new practice-level payment, which would support patients with terminal illness to access holistic support from their general practice through a palliative approach. The practice would assist with advance care planning, developing goals of care, and referring family to social supports – including activities that are currently not billable to Medicare.

The actions proposed below are consistent with the recommendations of recent reviews commissioned by the Australian Government, including the *Review of General Practice Incentives* and *Unleashing the Potential of our Health Workforce: Scope of Practice Review*.

PCA is calling on the Australian Government to:

- **Establish a new quarterly payment to primary care practices**, for each patient of the practice diagnosed with a life limiting illness and with a life expectancy of 12 months or less, where that patient has at minimum had a care plan completed or reviewed in the past 6 months. This payment would cover activities undertaken by multidisciplinary team (MDT) members that **cannot be billed to Medicare**.
- **Promote greater use of existing MBS items** by GPs and multidisciplinary primary care teams to ensure that complex care planning and co-ordination is delivered at end of life. This could be achieved by providing additional guidance on the recently introduced Level E 60 minute consultation, and the existing Level D and Level C consultations, to be more explicit about their use for palliative care. **PCA supports the RACGP's call** for an uplift in the Level D and Level C rebates to encourage GPs to spend more time with patients who may otherwise miss out on the care they need.
- Establish supplement payments (or new MBS items, or new guidance on existing MBS items) to recognise the costs involved in undertaking the following for palliative patients:
  - **Home visits** where someone is unable to travel without patient transport, including potentially multiple home visits in the terminal phase of care, with allowance made for travel time.
  - Services delivered **after hours**, and on-call availability after hours.
  - **Medical certification of death**.
  - Participation in **shared care** with health professionals from specialist palliative care services (for example palliative care nurses conducting home visits).
- Establish an **expert working group** to provide further advice to the Australian Government on promoting palliative care in primary care, by:
  - Considering additional or amended payment structures which might increase access to quality palliative care in primary care.
  - Recognising and incentivising professional development in palliative care among MDT members, for example via payments to reflect training undertaken.
  - Reviewing the comparative remuneration for delivering palliative care available to GPs, palliative medicine specialists and other medical specialists through the MBS, including for shared care.
  - Considering quality safeguards for primary care practices that claim additional remuneration for palliative care, for example with reference to the National Palliative Care Standards for All Health Professionals and Aged Care Services.
  - Establishing pathways for GPs to pursue formal qualifications for extended skills in palliative care.
  - Exploring incentive structures to promote the recognition of skills and experience in palliative care across disciplines working in primary care.
  - Consider how payment structures can achieve an appropriate balance between the needs of patients in different circumstances, such as those in residential aged care.
  - Identifying and scaling up promising locally-developed models of care, informed by the evaluation of the Greater Choice for At Home Palliative Care Program.
- In recognition of the gap in knowledge and data regarding palliative care in Australian primary care settings, develop a **Palliative Care in Primary Care Monitoring and Evaluation Framework**, and ensure that palliative care is explicitly covered in other government-led initiatives to generate primary care data to inform policy and practice.

2. Better access to critical palliative care medicines

Growing shortages of essential palliative care medicines in Australia are having **a devastating impact on patients, especially those nearing the end of life**, and the clinicians who care for them.

Patients are suffering unnecessarily, enduring heightened pain and distress, because the medications that typically control their symptoms are either unavailable or prohibitively expensive. This is especially heartbreaking for people in their final days or weeks, when comfort and dignity are paramount.

Most of the affected medicines are vital opioid analgesics that have been used for decades to manage severe pain and other symptoms in palliative care patients. With the supply of these drugs becoming increasingly uncertain, clinicians are forced to prescribe less effective alternatives, resulting in less reliable pain relief and risking unwanted side effects.

"Use of a particular medicine is supported by experience, education, and evidence – but instead **we find ourselves needing to ring around and find supplies**, adding medical appointments, getting scripts, relearning a new medication regimen – and having to communicate that to people at a time where they are unwell"

– Prof Meera Agar, practising palliative care physician in south-west Sydney, PCA Chair

"The ongoing difficulty with **access to reliable medications has been a concern**, particularly as these are medications that our clinicians feel comfortable with and have experience using."

– Dr Peter Alcroft, palliative care specialist working in southern Adelaide, PCA Deputy Chair.

This situation has been building for several years, and has become especially challenging in the past 12 months with the withdrawal of Ordine morphine oral liquid from Australia by its supplier, Mundipharma. While that situation is close to resolution, Ordine is just the latest in a series of opioid analgesics with supply disruptions, with more on the horizon.

Doctors, nurses, pharmacists and carers are caught in a cycle of frustration, having to continually adjust treatment plans and procurement arrangements based on shifting availability of medications. These frequent changes can lead to confusion, mistakes, and suboptimal care, particularly in rural settings where accessing substitute medicines is even more challenging.

Families, already grappling with the emotional toll of a loved one's decline, are often left navigating these disruptions, with the added stress of figuring out alternatives, often at substantial financial cost where alternatives are not available on the PBS.

"It is so **sad that this hasn't been addressed and managed properly**. As someone with an elderly mother needing regular Ordine, the stress of accessing it has exacerbated our stress."

– Carer

"Having to change to different medications at this stage of people's lives **is very challenging for them** as the alternatives are often not as effective."

– Carer

For example, a bottle of Ordine would normally cost concessional patients a $7.30 PBS co-payment ($30 for general patients). If the alternative is not listed on the PBS, patients would have to pay the full price, which could be up to $100 for some of the alternatives. A more startling example is hydromorphone SR, which costs the public $182 for 32mg. **The overseas alternative, which is not PBS-listed, is $4209 for 100 tablets – 23 times more expensive!**

What clinicians say

"As a palliative care nurse who has an elderly mother needing regular Ordine [morphine oral liquid] **the stress of accessing it has exacerbated an already stressful time.** So sad when it was a planned shortage that not enough was done to prevent this happening."

"Having to change to different medications at this stage of people's lives is very challenging for them and the alternatives are often not as effective. One way to add pressure to the broken hospital system as more **people are forced to present to ED** when previously we could manage their symptoms at home."

"Patients [who are] unable to get liquid morphine [and are] **ending up in EDs** instead of spending time in their place of preference."

"I had a patient who requested to remain at home for end-of-life care. The patient's daughter... **rang many chemists but was unable to locate one** who had the stock [of low dose oral morphine]. With joint effort from the GP, community palliative care team and the daughter, we found an available supply in a private hospital pharmacy. However, the supply was no longer available by the following day... **It was extremely distressing for the family**, who was... putting up with the pain from advanced cancer."

"Clients are unable to access any morphine liquid, there is even some difficulty accessing Oxynorm as an alternative. **There are cost implications as alternatives are not PBS listed** as well as implications for inadequately managed symptoms."

PCA's plan for better access to critical palliative care medicines

Despite sector representations to the Minister for Health, the TGA and the Department of Health and Aged Care, there has been little progress toward ensuring a stable supply of these life-changing drugs.

Health stakeholders including PCA have developed an **11-point plan** to address shortages of palliative care medicines, including fully subsidising medicines prescribed through the Palliative Care Schedule.

With 1.3 million scripts filled under the Palliative Care Schedule in 2022-23[26] (93% on a concessional basis), it is estimated the cost to the Australian Government would be $14.8 million per annum.

Making palliative care medicines free for people at the end of life would put this money in the pockets of Australian families struggling with the impact of terminal illness.

The cost of fully subsidising medicines on the PBS Palliative Care Schedule, medicines which have typically been used clinically for decades, is very low compared with the billions of dollars the Government spends each year on subsidising the cost of newly introduced medicines.

We are also calling on government to create a $10 million fund to establish a national stockpile of critical medicines where there are risks to supply.

The **11-point plan** aligns strongly with current "Made in Australia" initiatives. Developing our sovereign medicine manufacturing capacity also stimulates local economies, safeguards the community from future global shocks and fosters a greater sense of national pride.

The **11-point plan** includes other actions to improve the effectiveness of the PBS Palliative Care Schedule, to manage temporary supply disruptions, and to manage long-term supply risks. It has been **endorsed by the following organisations**, who have written a joint open letter to the medical doctors in the Australian Parliament and appealed to their medical ethics, asking them to spearhead the changes:

- **Palliative Care Australia**
- **Australia New Zealand Society of Palliative Medicine**
- **Advanced Pharmacy Australia**
- **Pharmaceutical Society of Australia**
- **Palliative Care Nurses Australia**
- **Pain Australia**
- **Aged and Community Care Providers Association**

11-point plan to resolve shortages of palliative care medicines

PBS Palliative Care Schedule

1. Add medicines on the PBS Palliative Care Schedule to the Medicines Watch List as critical medicines.
2. Review and update the PBS Palliative Care Schedule, based on clinical advice, to include all medicines commonly used in palliative care.
3. Waive application fees for sponsors seeking to list medicines on the PBS Palliative Care Schedule and/or opioid analgesics on the PBS.
4. Ensure that any medicines prescribed under the PBS Palliative Care Schedule that require an authority are available via a streamlined authority.
5. Abolish co-payments for medicines prescribed through the PBS Palliative Care Schedule.

Managing temporary supply disruptions

6. Expand the powers of the TGA to more proactively anticipate shortages and discontinuations of critical medicines and intervene more proactively, including by initiating the creation of stockpiles of identified medicines in need.
7. Establish a fund (with an initial commitment of $10 million) to enable the Australian Government to create and manage a stockpile of palliative care medicines through the established network of Community Service Obligation (CSO) distributers.
8. Extend the timeframe for notifying the TGA of any anticipated shortage, discontinuation or disruption to supplies of medicines on the Palliative Care Schedule from 6 months to 12 months, and enforce civil penalties against sponsors who do not meet their obligations under the Medicine Shortage Reporting Compliance Framework.
9. Commission an independent evaluation of whether arrangements through Section 19A of the Therapeutic Goods Act 1989 are achieving the intended purpose and how they could be strengthened to mitigate temporary medicines shortages.

Managing long-term supply risks

10. Expand incentives for domestic pharmaceutical manufacturing to essential medicines in common clinical use, including opioid analgesics.
11. Commission an objective assessment of the factors contributing to the longer-term decline in the availability of opioid analgesics in Australia. This should include consideration of the comparative conditions of the Australian versus other markets with respect to factors such as price, costs of registration, compliance with regulations for Schedule 8 medicines (e.g. security, medicines handling, administration, distribution).

Further detail on the 11-point plan to resolve shortages of palliative care medicines can be found on the Palliative Care Australia website.

3. Better access to palliative care in aged care

The Royal Commission into Aged Care Quality and Safety said palliative care must become "core business" in aged care. It has been six years since the Royal Commission commenced, and despite positive reforms, **there is still much to do to reach this goal**.

On the evidence available we cannot yet say that access to palliative care in residential aged care has improved since the Royal Commission. The next chapter of reform must have palliative care at its heart.

Around thirty percent of all Australian deaths occur in residential aged care,[27] rising to half of all deaths among those aged over 85.[28] On average, people live in residential aged care for just over two years after they enter;[29] most deaths in residential aged care are caused by life-limiting illness; and almost all residents have at least one life-limiting condition.[30]

There are around 185,000 people living in residential aged care.[31] Of those people:

92%
would benefit from palliative care[31]

Only 1/3
receive a GP health assessment in their first year[34]

Only 3%
see a palliative care doctor in their first year[33]

Only 0.1%
entered to receive palliative care[32]

This is just not good enough and we must do better for our loved ones.

As the Australian population ages, the health needs of people receiving aged care services are becoming more complex, both in residential aged care and for those ageing in place.

The numbers of people receiving home-based aged care grew fourfold in the decade to 2023,[35] reflecting strong community preference to receive care at home for as long as possible. Our aged care and health care systems are yet to fully adapt to this reality. Services and professionals need support and investment to innovate and meet this growing need for home care.

Australia's new Aged Care Act is expected to include a right to equitable access to palliative care and end-of-life care when required for all people using or seeking funded aged care services. To achieve this right for older Australians using aged care services, we need continued focus on improving access to palliative care in aged care.

What aged care workers say

Among respondents to PCA's 2024 National Workforce Survey:

- 80% of aged care workers said the service where they work has experienced increased demand for palliative care in the last year.
- The majority of aged care workers (56%) did not think the delivery of quality of palliative care has improved in the aged care service where they work in the last 1-2 years
- One in eight aged care workers (12%) said the delivery of quality palliative care in the service where they work had deteriorated in the last 1-2 years.

When asked about the most significant challenges for the palliative care workforce, aged care workers said:

"Having **nurses and care staff actually know what effective palliative care is** and how to deliver it."

"The **lack of understanding** of what palliative care is - for many they just see/think/hear that it is about the last days of life."

"**Lack of understanding and knowledge** of palliative care among new graduated nurses."

"Recognition in aged care that **palliative care is not just end of life care** - significant opportunities are missed."

When asked about the opportunities to improve access to palliative care, aged care workers said:

"**Annual education** for ALL staff."

"RN and personal care workers **mandatory orientation and education** in palliative care."

"**Mandatory rotation** of nursing staff through palliative care. At least upskilling general workforce."

PCA's plan to improve access to palliative care in aged care

- PCA calls on the Australian Government to **invest $32.8m over three years to train 15,115 nurses** working in residential care and home support, including backfilling and travel costs for those working in remote areas to undertake placements. This would provide training for nurses providing 24/7 care in every residential aged care facility and all nurses providing clinically complex home care. It would also leverage Australian Government investment in existing palliative care training programs.
- PCA is also calling on the Australian Government to **establish an independent, two-yearly public report on palliative care in aged care**, to provide objective information on whether access to palliative care is improving for older people. The report would cover:
  - Aged care workforce capability to provide palliative care
  - Equitable access to palliative care in aged care
  - Completion, quality and clinical useability of Advance Care Plans and Directives.
- Finally, PCA believes **aged care services need to be funded to better identify and respond to people's palliative care needs much sooner**.
- The first step would be to lower barriers to accessing funding through the existing palliative care classification (known as the Australian National Aged Care Classification, Class 1). This would mean funding would be available to provide palliative care for residential aged care users **based on care needs, not prognosis**. Currently, many people with advanced terminal illness are excluded from funded care where their prognosis is uncertain or longer than three months. PCA also proposes amending funding structures so that existing aged care residents can be classed as palliative – not just new residents.

4. Better access to support at home for people under 65 with a life-limiting illness

PCA estimates that **at least 5,000 people under 65 currently have no access to basic day-to-day functional supports** for a disability stemming from a terminal diagnosis. This group is caught in the funding gaps between the NDIS, the aged care system and state/territory health systems.

These are vulnerable Australians who need basic support with the activities of daily living so they can remain at home in their last months or weeks of life.

These people are at high risk of being admitted to hospital or residential aged care, not because they need round-the-clock clinical care, but because they can't remain at home safely without basic non-clinical support. This ultimately costs governments far more money and is distressing for all concerned.

What consumers and carers say

"We felt **completely unsupported** and without options."

– Young mum, caring for her husband

"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.

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

– Mum, early 40s, in hospital separated from family

What the Independent NDIS Review said

"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."[36]

PCA's plan to improve access to at-home support for people under 65

PCA calls on the Australian Government to establish a program of non-clinical care and support for people under 65 living with a terminal illness, including those with a disability, who need support with the activities of daily living to remain at home and out of hospital. In most cases the NDIS cannot and is not designed to provide this support.

The proposed program would complement existing clinical care by filling current gaps in basic non-clinical and functional support.

A grant for this program would **support approximately 5,000 people each year, and has been costed at $136.3 million over 3 years**. PCA stands ready to assist with delivering the program by working with our national network and the wider palliative care sector to commission services from accredited providers.

This approach is proposed as an interim solution, to allow time for a longer-term cross jurisdictional approach to be developed.

PCA also calls on the Australian Government to clarify its long-term plan to fill this service gap. Without a plan, this group of vulnerable Australians will die without access to the basic care and support they need to live with dignity in their final months or weeks. A long-term solution may be part of the system of Foundational Supports, announced by National Cabinet in December 2023 but yet to be detailed.

What is palliative care?

PCA and the Australian Government subscribe to the World Health Organisation's definition of palliative care:

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Who is Palliative Care Australia?

Palliative Care Australia is the national peak body for palliative care. PCA represents those who work towards high quality palliative care for all Australians who need it.

Working closely with consumers, and our 12 member organisations, we work together to improve access to, and awareness of palliative care.

Our members are:

Palliative Care Nurses Australia
Australia New Zealand Society of Palliative Medicine
Palliative Care Social Work Australia
Paediatric Palliative Care Australia & New Zealand
Palliative Care Queensland
Palliative Care NSW
Palliative Care ACT
Palliative Care Victoria
Palliative Care Tasmania
Palliative Care South Australia
Palliative Care Western Australia
Palliative Care Northern Territory

References

[1] Australian Institute of Health and Welfare, May 2024, National Palliative Care Measures at: https://www.aihw.gov.au/reports/palliative-care-services/national-palliative-care-measures/contents/measures

[2] *Australian Institute of Health and Welfare, November 2023, Palliative care services in Australia, Workforce at:* https://www.aihw.gov.au/reports/palliative-care-services/palliative-care-services-in-australia/contents/palliative-care-workforce *(reports 1.2* FTE palliative care physicians nationally per 100,000 people, well below *the benchmark of 2.0 FTE per 100,000 population for specialist palliative care clinicians set in* Palliative Care Australia's 2018 *Palliative* Care Service Development Guidelines.

[3] *Australian Institute of Health and Welfare*, November 2023, Palliative care services in Australia, Workforce at: https://www.aihw.gov.au/reports/palliative-care-services/palliative-care-services-in-australia/contents/palliative-care-workforce

[4] Australian Institute of Health and Welfare, May 2024, Palliative care and health service use for people with life-limiting conditions, Predictable Deaths Population at: https://www.aihw.gov.au/reports/palliative-care-services/health-service-use-people-life-limiting-conditions/contents/methods/study-populations.

[5] Australian Institute of Health and Welfare, May 2024, Palliative care and health service use for people with life-limiting conditions, at: https://www.aihw.gov.au/reports/palliative-care-services/health-service-use-people-life-limiting-conditions/contents/summary

[6] Australian Bureau of Statistics, Population Projections, Australia, (2022–2071) at:

https://www.abs.gov.au/statistics/people/population/population-projections-australia/latest-release

[7] Australian Institute of Health and Welfare, GEN Aged Care Data, June 2023, People leaving aged care at: https://www.gen-agedcaredata.gov.au/topics/people-leaving-aged-care

[8] Australian Institute of Health and Welfare, June 2021, Interfaces between health and aged care systems, where do older people die? at: https://www.aihw.gov.au/reports/aged-care/where-do-older-australians-die/summary

[9] Australian Institute of Health and Welfare, GEN Aged Care Data, June 2023, People leaving aged care at: https://www.gen-agedcaredata.gov.au/topics/people-leaving-aged-care

[10] Australian Bureau of Statistics, November 2023, Population Projections, Table 1, Population projects, components of change and summary statistics, Australia, at: https://www.abs.gov.au/statistics/people/population/population-projections-australia/2022-base-2071#data-downloads

[11] Australian Bureau of Statistics, November 2023, *Life Expectancy 2020-22,* at: https://www.abs.gov.au/statistics/people/population/life-expectancy/2020-2022

[12] Australian Government, 2023, Intergenerational Report (p6) at: https://treasury.gov.au/publication/2023-intergenerational-report

[13] KMPG, 2020. Investing to Save: The economics of increased investment in palliative care in Australia. Palliative Care Australia and KPMG.

[14] *Australian Institute of Health and Welfare, November 2023, Palliative care services in Australia, Workforce at:* https://www.aihw.gov.au/reports/palliative-care-services/palliative-care-services-in-australia/contents/palliative-care-workforce *(reports 1.2* FTE palliative care physicians nationally per 100,000 people, well below *the benchmark of 2.0 FTE per 100,000 population for specialist palliative care clinicians set in* Palliative Care Australia's 2018 *Palliative* Care Service Development Guidelines.

[15] 4*Australian Institute of Health and Welfare*, November 2023, Palliative care services in Australia, Workforce at: https://www.aihw.gov.au/reports/palliative-care-services/palliative-care-services-in-australia/contents/palliative-care-workforce

[16] Australian Institute of Health and Welfare, May 2024, National Palliative Care Measures at: https://www.aihw.gov.au/reports/palliative-care-services/national-palliative-care-measures/contents/measures

[17] Australian Institute of Health and Welfare, May 2024, Palliative care and health service use for people with life-limiting conditions, at: https://www.aihw.gov.au/reports/palliative-care-services/health-service-use-people-life-limiting-conditions/contents/summary

[18] Agar M, Currow D, Shelby-James T, Plummer J, Sanderson C and Abernethy A (2008), Preference for place of care and place of death in palliative care: are these different questions?, in Palliative Medicine 2(7) 787-795; and Pinto, S, S Lopes, A de Sousa, M Delalibera and B Gomes (2024), Patient and family preferences about place of end-of-life care and death: an umbrella review, in Journal of Pain and Symptom Management 67(5), May 2024,

[19] Australian Bureau of Statistics, April 2021, Classifying Place of Death in Australian Mortality Statistics at: https://www.abs.gov.au/statistics/research/classifying-place-death-australian-mortality-statistics

[20] Australian Bureau of Statistics, April 2021, Classifying Place of Death in Australian Mortality Statistics at: https://www.abs.gov.au/statistics/research/classifying-place-death-australian-mortality-statistics

[21] KMPG, 2020. Investing to Save: The economics of increased investment in palliative care in Australia. Palliative Care Australia and KPMG (p73)

[22] Australian Institute of Health and Welfare, June 2024, *National Palliative Care Measures*, *Avoidance of Overtreatment, Measure 2.1, Figure 2.1.1.* at: https://www.aihw.gov.au/reports/palliative-care-services/national-palliative-care-measures/contents/safe/measure-2-1-avoidance-of-overtreatment

[23] Independent Hospital and Aged Care Pricing Authority, 2023, National Hospital Cost Data Collection 2020-2021, Appendix Tables, Table 7.

[24] Department of Health, March 2017, Research into awareness, attitudes and provision of best practice advance care planning, palliative care & end of life care within general practice, Charles Coulton & Catherine Boekel for Where to research.

[25] Australian Government, 2024, Features of the new support at home program, End-of-Life Pathway at: https://www.health.gov.au/our-work/support-at-home/features#:~:text=The%20new%20End%2Dof%2DLife,End%2Dof%2DLife%20Pathway.

[26] Australian Institute of Health and Welfare, October 2024, Palliative Care Services in Australia, Palliative Care Related Medications at: https://www.aihw.gov.au/reports/palliative-care-services/palliative-care-services-in-australia/contents/palliative-care-related-medications

[27] Australian Bureau of Statistics, April 2021, Classifying Place of Death in Australian Mortality Statistics at: https://www.abs.gov.au/statistics/research/classifying-place-death-australian-mortality-statistics

[28] Australian Institute of Health and Welfare, June 2021, Interfaces between health and aged care systems, Where do older people die? at: https://www.aihw.gov.au/reports/aged-care/where-do-older-australians-die/summary

[29] Australian Institute of Health and Welfare, GEN Aged Care Data, June 2023, *People leaving aged care* at: https://www.gen-agedcaredata.gov.au/topics/people-leaving-aged-care

[30] Humphrey G, Inacio M, Lang C, Churches O, Sluggett J, Williams H, Morgan D, To T, Kellie A, Wesselingh S, Caughey G, May 2024, Estimating potential palliative care needs for residential aged care: A population-based retrospective cohort study in Australasian Journal on Ageing, 2024;00:1-10, https://doi.org/10.1111/ajag.13345

[31] AIHW, Gen Aged Data, Aged Care Admissions, 2022-2023 at: https://www.gen-agedcaredata.gov.au/topics/admissions-into-aged-care#Aged_care_admissions_in_2022-23; Humphrey G, Inacio M, Lang C, Churches F, Sluggett K, Williaman H, Morgan D et al June 2024, Estimating potential palliative care needs for residential aged care: A population-based retrospective cohort study, in Australasian Journal on Ageing 2024;00:1-10, https://doi.org/10.1111/ajag.13345

[32] Australian Institute of Health and Welfare, GEN Aged Care Data, *People's care needs in aged care,* 30 August 2024 at: https://www.gen-agedcaredata.gov.au/topics/people-s-care-needs-in-aged-care

[33] Caughey, G et al, February 2024, Primary health care service utilization before and after entry into long-term care in Australia, in Archives of Gerontology & Geriatrics Volume 117, https://doi.org/10.1016/j.archger.2023.105210

[34] Caughey, G et al, February 2024, Primary health care service utilization before and after entry into long-term care in Australia, in Archives of Gerontology & Geriatrics Volume 117, https://doi.org/10.1016/j.archger.2023.105210

[35] Australian Institute of Health and Welfare, GEN Aged Care Data, July 2024, People using aged care at: https://www.gen-agedcaredata.gov.au/topics/people-using-aged-care

[36] Commonwealth of Australia, Department of the Prime Minister and Cabinet, 2023, *Working together to deliver the NDIS. NDIS Review: supporting analysis* (p.137)

Palliative Care
Australia

Better access to palliative care
Worth voting for