Palliative Care Australia
Matters of life and death

2025 Progress Report on Implementation of the Aged Care Royal Commission Recommendations

Submission to the Office of the Inspector-General of Aged Care

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1. About Palliative Care Australia

Palliative Care Australia (PCA) is the national peak advocacy body for palliative care. PCA represents all those who work towards high-quality palliative care and end-of-life care for all Australians who need it. Working closely with consumers, our Member Organisations, national health stakeholders, and the palliative care workforce, PCA aims to improve access to and promote palliative and end of life care.

2. This submission

PCA values the opportunity to provide advice to inform the Office for the Inspector-General for Aged Care's 2025 *Progress Report on the Implementation of Aged Care Royal Commission Recommendations*.

In this submission, we focus on 12 Royal Commission Recommendations that relate directly to palliative care. These fall into four broad areas:

- **Legislative and regulatory framework** (Recommendations 2 and 19)
- **Care classifications and funding**
    - In residential aged care (Recommendation 37)
    - In home care (recommendations 35, 93 and 118)
- **Access to health care**
    - Integrated health and aged care provision; and better alignment between Commonwealth and state/territory funded services (Recommendations 58, 69 and 70)
    - Alternatives to aged care for people under 65, including those who require palliative care (74)
- **Workforce training** (Recommendations 79 and 80).

There have been important and welcome reforms in each of these areas. However, further work is required to bring about the system-wide improvement in access to quality palliative and end-of-life care that the Royal Commission envisaged.

3. Issues

Four years since the publication of the Royal Commission's Final Report, many significant aged care reforms are either in place or underway. These reforms reflect the expectation that palliative care and end-of-life care are "core business" in aged care, consistent with the relevant recommendations of the Aged Care Royal Commission.

Significant reforms to note are:

- The new Aged Care Act includes a right to equitable access to palliative care and end-of-life care for all people using and seeking Commonwealth-funded aged care *(consistent with Royal Commission Recommendation 2)*.
- Strengthened Aged Care Quality Standard 5.7 *Palliative Care and End of Life Care* will apply to all aged care services offering nursing or transition care, and Standard 3.1.6. sets appropriate expectations that aged care services will undertake Advance Care Planning (from 1 July) *(consistent with Recommendation 19)*.
- In residential aged care, the Australian National Aged Care Classification (AN-ACC) funding model includes AN-ACC Class 1, designed to provide adequate funding for the high care needs of people entering residential aged care for the purpose of receiving planned palliative care (*consistent with Recommendation 37)*.
- The new Support at Home program (commencing 1 July 2025) will include a short-term End-of-Life Pathway *(consistent with Recommendation 35 and 118)*.
- The Australian Government continues to support training and education initiatives designed to increase workforce and organisational capacity to provide palliative care within aged care *(consistent with Recommendations 79 and 80)*.

These changes contribute to an enabling environment for better palliative care in aged care.

However, reforms to date have not delivered tangible improvements in access to palliative care at the necessary scale. This reflects:

- The early stage of key reforms, many of which do not commence until July this year.
- Policy and program design choices that limit access to palliative care – in particular, eligibility for palliative care pathways in residential care and home care should reflect *clinical need* rather than the current, restrictive, prognosis-based eligibility criteria. This would better align with the Royal Commission's vision of rights-based access to palliative care, when needed.
- Aged care workforce challenges (recruitment, retention and skills development), including a significant need for training and education to support provision of a palliative approach in home care and in aged care facilities.
- Slow progress on reforms designed to better integrate palliative care and aged care service provision, including assuring ongoing funding for specialist palliative care outreach services into aged care through the next National Health Reform Agreement Addendum (as per Royal Commission recommendations 69 and 70).
- Lack of systematic collection of data about the delivery of palliative care and end-of-life care in aged care, making it very difficult to draw evidence-based conclusions about access, quality of care, or change over time.

In each area of reform (legislation and regulation, classifications and funding, training and education, and integrated health and aged care services), these challenges limit the extent to which the Royal Commission's vision has been realised to date. These are detailed in the attached **Appendix**.

4. Recommendations

To build on reforms to date and strengthen palliative care in aged care in line with Royal Commission's vision, PCA makes the following recommendations:

Legislation and regulatory framework

- OIGAC consider wait times, including for palliative care needs assessment and reassessment, as an issue for continued focus.
- The Australian Government commission an independent, two-yearly report on palliative care in aged care, to provide an objective measure of progress. The Office of the Inspector General for Aged Care is well-placed to provide a regular, independent and transparent assessment of the extent to which the right to palliative care and end-of-life care is achieved over time in the aged care system.

Care classifications and funding

- Eligibility for palliative care specific pathways (AN-ACC Class 1 in residential aged care, and the Support at Home End-of-Life Pathway) be changed to reflect *clinical need* rather than restrictive prognosis-based criteria
- IHACPA investigate whether the AN-ACC funding model adequately reflects the costs of comprehensive palliative care delivery in residential aged care.
- An exceptions process be put in place so that the Department of Health and Aged Care can approve an extension of time for people who outlive the Support at Home End-of-Life Pathway's limited timeframe (12-16 weeks).
- The Support at Home End-of-Life Pathway undergo independent evaluation one year after commencement, to ensure it is achieving its stated intent.

Workforce education and training

- Workforce skills in palliative care be supported through continued access to Australian Government-supported training programs, introduction of required palliative care competencies, and additional government investment to enable aged care providers to release frontline staff to attend training and backfill their positions. Uplift in home care workforce skills is a priority.

Integrated health and aged care services

- All governments take the opportunity presented by the ongoing negotiation of the next NHRA Addendum, to provide secure funding for initiatives to better integrate health and aged care, including specialist palliative care outreach models (as per Royal Commission recommendations 58 and 69).
- A program of non-clinical support for people under 65 who have terminal illness and high functional needs (but who are not NDIS eligible) be put in place urgently, to meet the needs of this group - who continue to seek care from the aged care system in the absence of appropriate services for younger people. This would provide an interim solution for approximately 5,000 people a year, pending a long-term intergovernmental agreement about a durable program response.

5. Concluding remarks

Aged care reforms in place, and in train, will support better access to palliative care in aged care. However, further work is needed to ensure that palliative care becomes "core business" in aged care. The attached appendix provides detail about PCA's view on progress and challenges in key areas: legislation and regulation, care classifications and funding, workforce training and education, and integrated health and aged care.

PCA looks forward to publication of the Office of the Inspector General for Aged Care's *2025 Progress Report*. This is an important opportunity for independent assessment of progress toward a rights-based and demand-driven aged care system, in which access to equitable and timely palliative care and end-of-life care is assured.

Please do not hesitate to contact PCA if you would like to discuss any aspect of this submission.

Attachment 1:

Progress toward Aged Care Royal Commission Recommendations related to palliative care and end-of-life care

This document identifies progress toward key palliative care-related recommendations of the Royal Commission into Aged Care Quality and Safety, across the areas of:

1. Legislative and regulatory framework
2. Care classifications and funding (residential aged care, and home support)
3. Workforce training and education
4. Integrated provision of health and aged care services.

These areas are addressed in turn.

1. Legislative and regulatory framework

The new Aged Care Act, which will come into effect from 1 July 2025, includes a right to equitable access to palliative care and end-of-life care for all people using and seeking Commonwealth-funded aged care (Recommendation 2). The Act's commencement will also allow other regulatory reforms to begin, including the strengthened Aged Care Quality Standards. These include Clinical Standard 5.7, *Palliative Care and End of Life Care,* which places clear requirements on providers of nursing and transition care to provide palliative and end-of-life care. The new Standards also set appropriate expectations for aged care providers to undertake Advance Care planning (Standard 3.1.6).

While the Act includes a right to aged care needs assessment, it does not include a right to timely *provision* of aged care services. Yet wait times are a significant challenge for people seeking or accessing aged care services. They also present a barrier to palliative care and end-of-life care in aged care. Timely assessment of need, timely commencement of services, and timely ongoing reassessment of changing requirements for care are crucial aspects of quality palliative care and end-of-life care.

Delay in aged care funding classification assessment is one particular challenge. Department of Health and Aged Care guidelines for residential aged care were updated in late 2024 to extend the timeframe for urgent funding classification reassessment for those nearing end of life (to 14 days). As the guidance acknowledges, this will be too late for many people requiring reassessment of their funding classification as they approach end of life. No information has been published to date to indicate likely timeframes for the high priority needs assessment that will be required prior to entering the Support at Home End-of-Life Pathway. Many family carers continue to experience long wait times for respite care, yet swift access to this care (with confidence that the full range of clinical and non-clinical palliative care supports is provided) is essential to ensure people can continue in their caring role.

PCA encourages OIGAC to prioritise wait times, including for palliative care needs assessment and reassessment, as an issue for continued focus.

2. Evaluation and data

The limited public data currently available does not give confidence that access to timely palliative care and end-of-life care is a reality for most older people using or seeking aged care services. For example, while an estimated 92% of people who die in residential aged care each year would benefit from palliative care,[1] just 0.1% of those living in residential aged care at June 2023 had entered in order to receive planned palliative care.[2] Surprisingly, this is lower than prior to the Royal Commission, when on average 6% of aged care residents each year were assessed as requiring palliative care under the previous ACFI instrument.[3]

There are many gaps in the publicly available data about palliative care in aged care. For example, we do not know:

- The palliative care needs of people living in residential aged care, other than for those assessed as eligible for the palliative care entry pathway (AN-ACC Class 1)
- Similarly, we will not know the palliative care needs of those accessing Support at Home services, other than for those participating in the short-term End of Life Pathway that commences in July 2025.

We also lack information about:

- How often, and how comprehensively, aged care services are assessing and re-assessing palliative care clinical and non-clinical care needs.
- How commonly tools to identify end-of-life care needs, such as SPICT, are used in aged care.
- How many aged care workers and professionals have undertaken basic introductory training in palliative care, and how many have undertaken advanced training (for example a post-graduate qualification with a palliative care specialisation).

In PCA's view, a framework for collecting, assessing, and sharing data about the provision of palliative care in aged care is essential, to provide objective information about whether access to palliative care is improving for older people.

PCA recommends this be undertaken via an independent, two-yearly public report on palliative care in aged care, commissioned by the Australian Government. The report would cover: 1) aged care workforce capability to provide palliative care 2) Equitable access to palliative care in aged care and 3) Completion, quality and clinical useability of Advance Care Plans and Directives held by aged care providers.

The new Aged Care Act requires implementation review at two years from commencement, and this presents an opportunity for a specific review of palliative care in aged care. The Office for the Inspector-

[1] 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, DOI: 10.1111/ajag.13345

[2] Australian Institute of Health and Welfare, GEN Aged Care Data, *People's care needs in aged care at 30 June 2023,* 30 August 2024 at: https://www.gen-agedcaredata.gov.au/topics/people-s-care-needs-in-aged-care.

[3] See note 1, above.

General for Aged Care is also well-placed to provide a regular, independent and transparent assessment of the extent to which the right to palliative care and end-of-life care is achieved over time in the aged care system.

PCA notes that data exists that could assist in forming a comprehensive view of the state of palliative care in aged care, including information held by the Australian Institute of Health and Welfare, and the Registry of Senior Australians. Highly relevant information is also held by the Palliative Aged Care Outcomes Program (PACOP) and the End of Life Directions in Aged Care (ELDAC) Program, collected from aged care providers who voluntarily participate in those Commonwealth-funded programs.

Other information will need to be routinely collected, including about the proportion of the aged care workforce that has completed palliative care training and education, the provision of palliative care needs assessments and re-assessments by aged care providers, and provision of palliative care across all AN-ACC Classes and Support at Home Classifications.

Appropriately, the AIHW GEN aged care dataset reports the numbers of people under 65 entering residential aged care, and their reasons for entry. To better understand progress toward Royal Commission 74 (no younger people in residential aged care), this dataset should ideally also include separate reporting on the numbers of people under 65 entering both permanent residential aged care, and short-term residential aged care (transitional and respite care) - in particular consecutive or frequent respite admissions. This information would provide a more comprehensive picture of use of residential aged care by this cohort, which includes people who enter to receive functional supports for an advanced life-limiting illness.

3. Care classifications and funding

3.1. Residential aged care

Consistent with Royal Commission recommendation 37, the Australian National Aged Care Classification (AN-ACC) funding model for residential aged care includes AN-ACC Class 1, entry for palliative care. This classification is designed to reflect the higher care requirements of people entering residential aged care to receive palliative care.

Around 100 people living in residential aged care in June 2003 were assessed as AN-ACC Class 1 – this is 0.1% of all aged care residents.[4] Yet almost all aged care residents will require palliative care (19% due to cancer, 61% to organ failure and 20% to frailty and/or dementia),[5] and it can be confidently assumed that many people enter residential aged care (assessed as AN-ACC Class 1-13) with high care needs associated with a life-limiting condition. This extremely low uptake, relative to overall need for palliative care in residential aged care, suggests the AN-ACC classification model is not yet working as intended to

[4] AIHW GEN Aged Care Data, Care Needs in Permanent Residential Aged Care, August 2024: https://www.gen-agedcaredata.gov.au/topics/people-s-care-needs-in-aged-care

[5] Figures are percentages of the 92% of aged care residents who it is estimated would benefit from palliative care, see: 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, DOI: 10.1111/ajag.13345

appropriately cost and support the care of those with high needs resulting from an advanced palliative diagnosis. Low uptake of AN-ACC Class 1 likely results from a combination of factors including:

- People must be prepared to make time-critical decisions and arrangements to enter aged care, and there must be a facility able to offer a high level of care sometimes at very short notice.
- Medical Practitioners and Nurse Practitioners, and aged care providers, report a lack of clarity about which aspects of the eligibility paperwork (Palliative Care Status Form) they are responsible for completing and submitting.
- Restrictive prognosis-based eligibility criteria limit access to AN-ACC Class 1.

Currently, eligibility is restricted to those assessed by an independent medical or nurse practitioner as having a life expectancy of three months or less, and high functional support needs (confined to bed at least half the time). This prognosis-based approach falls short of best practice needs-based clinical care assessment. Medical estimation of life expectancy is inherently difficult, particularly so when patients are frail aged people, or diagnosed with non-malignant illnesses. Limiting eligibility to those with a 3-month life expectancy also excludes those with very high functional support needs but a life expectancy of longer than 12 weeks – for example people with advanced neurodegenerative conditions.

PCA recommends that eligibility for AN-ACC Class 1 should be based on clinical need rather than prognosis.

This would recognise that many people have an advanced terminal diagnosis and a clear clinical and/ or social need to enter residential aged care for the purpose of receiving palliative care, while not having a life expectancy that can be confidently estimated at under 12 weeks.

Outside of AN-ACC Class 1, the palliative care and end-of-life care needs of people living in residential aged care remain ill-defined in the AN-ACC classification model. Nor is it clear to what extent palliative care needs assessment is routinely conducted by aged care providers as part of care planning or reassessment. People with palliative care requirements of varied levels of acuity will likely be found in all AN-ACC classes, but these needs are not reflected in AN-ACC classifications or branching (outside of Class 1), and this makes it very difficult to judge whether these needs are adequately met at either the system or the service level. It also makes it difficult to identify whether palliative care costs are sufficiently accounted for in the residential aged care pricing framework. While AN-ACC 'compounding factors (such as those captured via the Australia Modified Karnofsky Performance Score and RUG-ADL), reflect information relevant to palliative care, they do not capture the range of direct care requirements that are relevant to people with palliative care needs - for example, complex symptom management (neuropathic pain, confusion, breathlessness), complex clinical needs (response to rapid deterioration, complex medicines regimes), additional nursing, personal care and allied health requirements, complex family and psychosocial support needs, and grief and bereavement support.

It is not clear that the AN-ACC funding model adequately reflects the costs of comprehensive palliative care delivery in residential aged care, and PCA recommends that this question be further explored, for example through investigation by IHACPA.

3.2. Home care

PCA strongly welcomes the inclusion of a short-term End-of-Life Pathway within the Support at Home program commencing from 1 July 2025. Consistent with the intent of Royal Commission Recommendations 35 and 118, this is intended to provide additional aged care services for those who wish to remain at home to receive end-of-life care. The Pathway will provide the highest level of home support (a budget of $25,000 to be expended over three months, with possibility to extend to 16 weeks if unspent budget remains).

This is a significant and positive reform, consistent with strong community preference to receive both palliative care[6] and aged care[7] at home for as long as possible with appropriate support. However the Pathway is likely to face implementation challenges, which must be managed for it to succeed.

Among these challenges is the reliance on prognosis-based eligibility criteria which mirror those in place for AN-ACC Class 1 in residential care. As in residential care, it appears likely that these criteria will contribute to under-use of the Pathway, as many people with high functional support needs but uncertain life expectancy will be excluded.

Additionally, the maximum time-frame of 16 weeks to expend the $25,000 budget means people who defy expectations and outlive the Pathway timeframe must undergo a support plan review to continue to access aged care end-of-life supports via an ongoing Support at Home classification. This creates potential for unnecessary and costly disruption to their care, at a time when continuity of supports should be the priority. Interruptions in care are likely to cause unplanned hospital visits when people experience lack of support for their daily needs and their condition deteriorates. The needs assessment process is also potentially intrusive for people receiving end-of-life care, and their families and carers.

In PCA's view, time limits on participation in the Support at Home End-of-Life Pathway should be removed, for those assessed as eligible. This will ensure those who are eligible to participate in the Pathway can continue to access additional end-of-life supports until they die, without potential interruption. This approach would recognise the variability of end-of-life illness trajectories, and it is consistent with the approach in residential care, where people who enter to receive planned palliative care must have an estimated life expectancy of 3 months or less but can continue to access supports under AN-ACC Class 1 until their death.

PCA also recommends an *exceptions process* be put in place, so that the Department of Health and Aged Care can approve an extension of time for those who outlive the Pathway timeframe.

[6] 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? Palliative Medicine 2(7): 787-795, in KPMG May 2020. Investing to save, the economics of increased investment in palliative care in Australia, p23; also 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, *Journal of pin and symptom management 67(5), May 2024, https://doi.org/10.1016/j.jpainsymman.2024.01.014*

[7] As indicated in a 267% increase the numbers of people receiving aged care at home in the decade to 2023, compared with a 5.9% increase for permanent residential aged care over that period, see AIWH GEN Aged Care Data, 28 June 2023, Aged Care Admissions 2021-22 Admissions into aged care - AIHW Gen (gen-agedcaredata.gov.au)

The Pathway's success will rely on strong partnerships and a coordinated approach between aged care services, and palliative care clinicians and services (whether primary care providers, specialist palliative care services, or other clinical specialist teams providing care to a person with a life-limiting illness). This coordinated approach will be essential to avoid situations in which health and aged care services and professionals each hold the other system responsible for providing services (such as clinical care, assistive technology or functional supports). Adequate funding for general practice, and specialist palliative care, to be involved in the care of Pathway participants, will be essential. Substantial uplift in the capacity of these systems is required, given existing demand for limited services – for example at present, on average people first receive specialist palliative care just 15 days before their death.[8] This indicates the substantial resourcing constraints affecting the clinical specialists who will provide expert care to Pathway participants.

Similar to the situation in residential aged care, people with palliative care needs will access Support at Home services at all levels of classification. Across the Support at Home program, the requirement for means-tested individual contributions to the costs of independence services (including personal care) and everyday living services (including domestic assistance) is likely to drive consumer decisions (on financial grounds) to defer or not take up, services that contribute to quality of life and wellbeing – ultimately leading to greater reliance of fully-subsidised clinical aged care services and avoidable deterioration in symptoms. As an example, lower use of personal care services (which attract an individual financial contribution) may mean deterioration in symptoms is not identified as early as possible, requiring more intensive clinical management.

Given the scale of the reform, PCA recommends the Support at Home End-of-Life Pathway undergo independent evaluation one year after commencement, to ensure it is achieving its stated intent.

PCA also encourages the Department of Health and Aged Care to share and publish information about uptake and use of the Pathway as swiftly as possible following its commencement, and regularly during its roll-out, to support early identification and resolution of implementation challenges.

4. Training and education

PCA acknowledges the Australian Government's continued support of palliative care education and training via a range of initiatives including:

- Program of Experience in the Palliative Approach – palliative care placements and training for the aged care sector
- Palliative Aged Care Outcomes Program – a national program supporting optimal end-of-life care in residential aged care
- Palliative Care Education Directory – a searchable list of palliative care education and training opportunities

[8] AIWH, Palliative care and health service use for people with life-limiting conditions, May 2024.

- Equip Aged Care Learning Package - includes free, 10 minute, introductory and refresher palliative care modules.

Palliative care content is now also included in the Certificate III, Individual Support, for those undertaking the aged care specialisation.

However, there are no requirements that *mandate* workforce training in palliative care, consistent with the intent of Royal Commission recommendation 80. In PCA's view, mandatory training requirements would support consistent delivery of a palliative approach in aged care. The national registration scheme for personal care workers, currently under development by the Department of Health and Aged Care, is one opportunity to clearly state relevant expectations.

PCA is aware that many aged care providers report significant difficulty releasing frontline clinical and personal care workers from direct care tasks to attend training. In PCA's view, the necessary workforce-wide uplift in palliative care skills cannot be achieved without additional investment to provide backfill to allow clinical staff (crucially, aged care nurses) to undertake palliative care training. An investment of $32.8m over three years would support 1,511 nurses to attend evidence-based palliative care training. This would provide intensive job-relevant introductory training for every nurse providing 24/7 care in residential aged care, and all nurses providing clinically complex home care. Home care is a particularly important area of focus for future investment in palliative care training, as a substantial uplift in capacity will be required in this area to meet future need.

PCA also notes the importance of further work to support health professionals working with older people to specialise in palliative care. This includes through mentoring models, access to advanced post-graduate training, and the development of recognised post-graduate qualifications in palliative care. Opportunities for nurses, social workers and other allied health professionals to specialise in this complex area of care (and take up advanced practice roles), will contribute to workforce capacity to meet current and future need for palliative care, including in aged care.

Additional investment is required to support aged care frontline workers to undertake palliative care training. Uplift in home care workforce skills in this area is a priority.

5. Integrated health and aged care

5.1 Progress toward relevant Royal Commission recommendations

Progress toward Royal Commission recommendations related to the need for integrated models of health and aged care has been slow.

While evidence-based models of integration between specialist palliative care and aged care services exist,[9] there does not currently appear to be a clear approach to ongoing joint Australian and

[9] For example palliative care needs rounds, see Forbat L, Liu WM, Koerner J, Lam L, Samara J, Chapman M, Johnston N. (2020). Reducing time in acute hospitals: A stepped-wedge randomised control trial of a specialist palliative care intervention in residential care homes. Palliative Medicine. 34(5):571-579. doi: 10.1177/0269216319891077; see also initiatives progressed by states and territories via the

state/territory government investment in specialist palliative care outreach, or multidisciplinary health outreach teams (involving geriatricians, psychogeriatric and palliative care specialists) (as per Royal Commission Recommendation 58).

Australian governments published a joint statement setting out the roles of aged care providers, state and territory health services, and governments in providing health and aged care services in mid-2024 (consistent with Recommendation 69). Unfortunately, the joint statement this does little to clarify how services and professionals should resolve situations when responsibility for provision of care is unclear, or where services are not available. More detailed guidance about responsibilities for integrated service provision, tailored to those providing services in health and aged care, is required.

The Royal Commissioners advised that both recommendation 58 (providing secure funding for palliative care outreach and multidisciplinary care teams), and recommendation 69 (clarifying the responsibilities of governments) should be incorporated into the NHRA Addendum.

The ongoing negotiation of the NHRA Addendum provides an opportunity to progress Royal Commission recommendations related to integrated health and aged care (Recommendations 58 and 69), which remain central to improving palliative care in aged care.

5.2. Younger people in, or at risk of admission to, residential aged care

Improving integrated provision of supports across systems is a particular priority for people aged under 65 who have high-level functional support needs arising from a life-limiting condition, but who are not eligible for the NDIS. These people cannot access sufficient supports from *any* relevant system: the new system of "foundational" disability supports outside the NDIS remains in the planning stage, and functional supports at the level required are not provided by state and territory health systems. People in this situation continue to look to residential aged care as the only remaining option, when informal supports fail.

The principle that aged care is not appropriate for younger people is now clearly reflected in age-based eligibility criteria for Commonwealth aged care services included in the Aged Care Act 2024. The Act introduces eligibility criteria that limit access to aged care to people aged 65 or over with care needs, and those aged 50 to 64 who have care needs and who are either Aboriginal or Torres Strait Islander, or are homeless or at risk. People under these age thresholds will need to have been advised of alternatives to aged care, and still express a wish to enter aged care, before they are eligible for funded aged care services. While consistent with the Royal Commission's vision of "no younger people in residential aged care", this change underscores the urgent need for better coordinated supports for younger people with high care needs, outside of aged care. This includes for younger people with high functional support needs resulting from a life-limiting diagnosis who are ineligible for NDIS support. Viable alternatives to aged care must be in place urgently.

Commonwealth Palliative Care in Aged Care measure: https://www.health.gov.au/resources/publications/comprehensive-palliative-care-in-aged-care-cpciac-measure-interim-report?language=en

PCA calls on government to explain how the needs of this group will be met outside of the aged care system in both the immediate and longer term.

As an interim solution pending a long-term intergovernmental agreement, PCA advocates for the establishment of a program of non-clinical care and support for people under 65 who have terminal illness and high functional support needs but are not NDIS eligible. This would complement existing clinical care by filling the current gap in basic non-clinical and functional support, and would assist an estimated minimum 5,000 people per year.

5. Final comments

As this discussion illustrates, important reforms are taking place across each of the areas in which the Royal Commission made recommendations directly related to palliative care. However, change to date has been stymied by factors including:

- Restrictive prognosis-based eligibility for palliative care pathways in residential care and home care.
- Need for significant workplace education and training to support provision of a palliative approach, particularly in home care.
- Slow progress on reforms designed to better integrate palliative care and aged care service provision, requiring intergovernmental agreement via the next National Health Reform Agreement Addendum (as per Royal Commission recommendations 69 and 70).
- Lack of systematic collection of data about the delivery of palliative care and end-of-life care in aged care, making it very difficult to draw evidence-based conclusions about access, quality of care, or change over time.

Further sustained work is required to bring about the system-wide improvement in access to quality palliative and end-of-life care that the Royal Commission envisaged.