



Dementia Australia and Carers Australia

A Joint Position Statement

August 2026



Dementia Australia and Carers Australia are calling for an urgent independent review of respite care services

Dementia Australia and Carers Australia are jointly calling for Australian Government leadership and investment in an independent review of the availability, quality, appropriateness and affordability of Commonwealth funded respite care services.

Recent government commitments through the National Dementia Action Plan and the National Carer Strategy recognise carers and respite as priorities. Respite is widely recognised as playing a critical role in sustaining informal care, maintaining wellbeing, preventing crisis, and supporting carers to participate in work and community life. However, carers, and especially carers of people living with dementia, consistently report that respite is unavailable, inaccessible and/or unsuitable.

Australia does not have a contemporary, nationally consistent understanding of respite demand, utilisation or unmet need. This impedes effective policy design and investment, particularly in the context of aged care and disability reforms and the National Carer Strategy.

Why respite is essential

Research and lived experience consistently demonstrate that respite is a critical support for carers and the people they care for.

Caring responsibilities are associated with higher levels of psychological distress, poorer physical health, social isolation and reduced wellbeing, particularly where caring is intensive or sustained over long periods.¹ Access to respite helps carers manage these pressures, reduce burnout, maintain social connection and sustain their caring role over time.²

Caring responsibilities significantly reduce workforce participation, working hours and long-term income, particularly for women and those providing high-intensity care.³ 42% of carers of people living with dementia provide 60 or more hours of unpaid care per week.⁴ Carers report that effective breaks from caring are critical to balancing paid work and other responsibilities.⁵

Respite can be equally as important for the people receiving care. Carers often identify respite as essential to sustaining home-based care arrangements, helping avoid crisis points that may otherwise result in hospitalisations or premature entry into permanent residential aged care.⁶

When these outcomes occur, they place additional strain on individuals and families and can also drive higher costs across the health and aged care systems. In this context, respite supports people to remain living safely at home and within their communities for longer.

Respite also improves quality of life for both carers and the people they support by enabling rest, social participation, independence and the ability to maintain relationships beyond the caring role.²

Despite these benefits, respite remains one of the most unmet needs across caring cohorts.⁵ For people impacted by dementia, these challenges are intensified. Respite may technically exist, but it is frequently limited, inflexible, difficult to navigate, or not dementia-appropriate, meaning that availability does not necessarily equate to genuine access. For many families, respite that exists “on paper” is not respite that can be safely or meaningfully used in practice.

Previously identified systemic respite challenges

The need for accessible, quality and appropriate respite has been repeatedly recognised across major national reform processes and policy frameworks.

The Royal Commission into Aged Care Quality and Safety identified limited access to respite as a systemic failure of the aged care system. It found that respite was often unavailable when carers needed it most, especially in crisis situations, and that carers of people living with dementia or complex needs were frequently unable to secure appropriate support. The Final Report recommended improved respite and flexible support because unpaid carers are critical to care sustainability, and failures in respite undermine carers’ capacity and older people’s ability to remain at home.⁷

The National Dementia Action Plan 2024–2034 recognises the critical role of carers and the importance of improving support pathways for people living with dementia and their families, including better access to post-diagnostic support and services that sustain caring relationships over time.⁸

The National Carer Strategy also highlights access to appropriate, flexible and timely supports, including respite, as essential to carers' health, wellbeing, economic participation and long-term sustainability.⁹

Current respite inadequacies

Despite longstanding recognition that respite access is critical, and repeated findings from major inquiries that reform is urgently needed, current evidence indicates that respite access remains inadequate and, in some areas, is deteriorating.

The 2025 Carer Wellbeing Survey found that carers are finding it increasingly difficult to access respite that is affordable, flexible and fit for purpose. In 2025:

- + 59% of carers reported difficulty finding high-quality respite
- + 54% of carers reported long wait times to access respite
- + 56% of carers reported difficulty affording respite services
- + 58% of carers reported lack of available services in their local area.¹

The Carer Wellbeing Survey highlights that carers of people with dementia are most likely to access respite care when compared to other conditions and that respite has the poorest access of all service types for carers of people living with dementia.¹ The 2024 National Carer Survey similarly identified planned respite and emergency respite as among the highest unmet needs, with carers of people living with dementia particularly affected.⁵ These findings reinforce that respite remains one of the most critical yet inaccessible supports for many carers. This also suggests that access challenges are not improving despite prior reform commitments.¹

The Inspector-General of Aged Care confirmed that many respite concerns raised by the Royal Commission remain unresolved. Emergency respite is still difficult to secure, with people with dementia, especially with changed behaviours or more complex needs, continuing to face the most significant barriers. Current funding and market structures incentivise permanent occupancy over respite with reports of residential respite being offered only on a “try before you buy” basis rather than as genuine short-term support.⁶

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I had a 3-month plan to move my mum into respite for 3 weeks. I had to put mum in a facility that is one hour away from our home and where mum lived because no facility locally would take mum unless it was respite to permanent. I was told this by several providers.

Carer

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Dementia Australia’s 2025 and 2026 consultations with carers, people living with dementia and client services staff provide further insights into how these failures are experienced in practice. Across metropolitan, regional and remote communities, participants described insufficient availability of centre-based, in-home, overnight and culturally safe respite. Thin markets in many rural and remote areas mean respite services may not exist at all. Even where services are technically available, dementia-capable options are often limited, particularly for people with young onset dementia or changed behaviours.

These challenges are often compounded for Aboriginal and Torres Strait Islander peoples. Limited availability of culturally safe services, workforce shortages, distance from Country, and a lack of locally available supports can create additional barriers to accessing respite, particularly in regional and remote communities.

People from culturally and linguistically diverse (CALD) communities may face different challenges, including a lack of culturally appropriate and linguistically inclusive respite options, limited availability of bilingual workers, and concerns that services do not always reflect cultural preferences, family structures and communication needs.

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Carers need more respite services, also having a bilingual workforce would be an asset for organisations that provide services in these areas.

Carer

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Carers are also concerned about the quality, safety and appropriateness of respite care services. A lack of dementia capability, inconsistent care quality and previous negative experiences can significantly undermine trust and reduce carers' willingness to use respite even when available.

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Until respite truly accommodates the needs of someone living with dementia it might give a carer time out but the person living with dementia suffers during that period.

Carer

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System navigation is a major barrier. Carers frequently report not knowing what respite services are available, where to find them, or how to access them. Information is fragmented across aged care, disability and carer support systems, while administrative processes are often complex, time-consuming and difficult to navigate.

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When you go online to access respite vacancies in your area, the listings are never up to date and very few specify whether they will accept dementia patients.

Carer

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It is so time consuming, confusing, and exhausting having to have different codes, phone numbers etc. and different assessments, on top of the need (so often) for various medical appointments / tests etc.

Carer

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Aged care system changes, including the transition to Support at Home, appear to have compounded this confusion with respite pathways becoming less clear or more siloed. Dementia Australia consultation feedback from the Support at Home transition indicates that recent system and pricing changes are shifting the burden of care onto families. Cottage and centre based respite are no longer funded through Support at Home and are instead only accessible through the Commonwealth Home Support Program (CHSP), meaning they are not a viable option for many people with higher-level needs or people need to access supports from two systems to receive the support they need. At the same time, increased provider fees and client contribution, assessment and allocation of package delays interim packages at 60% of package value and removal of the dementia and cognition supplement are forcing older people and their carers to reduce or prioritise essential supports. As services are scaled back or become unaffordable, carers are increasingly filling gaps in care, contributing to significant strain, burnout and growing unmet need for respite.

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As the sole carer for someone with dementia what I really need is more respite hours so that I don't burnout. Respite is now so expensive under this new system I can only afford 2 hours a week. Absolutely not enough, and he is declining and it is becoming more demanding and exhausting as time progresses. I will be burnt out soon and then no one left to care for him.

Carer

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Where respite does exist, it often does not align with carers' needs. Inflexible hours, limited emergency options, workforce shortages and service models that do not accommodate employment or crisis situations mean respite is often unavailable when it is most needed. In many cases, service environments and delivery models are not designed to support people with dementia, including unfamiliar settings, lack of continuity, and limited dementia capability. As a result, respite that exists “on paper” may not be usable or appropriate in practice.

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Planned respite is the SINGLE most unacceptable lack in aged care services. I cannot believe it has not been planned for and executed since the beginning of these services.

Carer

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Unable to plan ahead and the fact that my husband does not want to go into respite preferring to stay at home with full time care which is very expensive even with a package.

Carer

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I have only had Respite care twice in 8 years. I would like to be able to forward plan and book a decent break once a year, but this is impossible. On one occasion I booked Respite care which was then cancelled.

Carer

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Similar issues are evident in disability systems. While respite supports may be available through mechanisms such as NDIS Short-Term Accommodation, access is highly dependent on plan funding, provider availability and local market capacity. People living with young onset dementia often report difficulties accessing respite that is both dementia-capable and age-appropriate, with limited service options available that reflect their stage of life, interests, support needs and preferences.

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I was at the stage of carer burnout, after caring for my husband for 5 years. For us to have funding put in the NDIS Plan we had to have an OT assessment which took months to access and then it was very hard to find respite care that suited a younger person with dementia. When we did receive funding, it was not adequate for what was needed.

Carer

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It seems that younger onset dementia people have far less options- they are funnelled into disability homes, and these environments are too unpredictable and noisy for people experiencing significant sensory processing problems.

Carer

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With the most recent proposed changes to the NDIS,¹⁰ there is a risk that tighter access, planning and funding arrangements will reduce or constrain supports for people living with dementia. Where supports are withdrawn, limited or not responsive to changing needs, caring responsibilities are likely to shift further onto unpaid carers, making access to appropriate and affordable respite even more critical.

There is also little evidence about respite for children living with dementia and their families. The Childhood Dementia Initiative reports that families often have almost no access to suitable respite services, with limited provider capability and little evidence regarding what safe, appropriate and desired respite models should look like in the paediatric context.

Taken together, this evidence suggests that respite access challenges are not isolated service gaps but represent ongoing systemic inadequacies across multiple care systems.

Respite provider barriers

Individuals approved for aged care residential respite care are entitled to up to 63 days of subsidised care per year (with possible extensions), although this represents an entitlement to funding rather than guaranteed access to a placement. At the same time, sector analysis indicates residential aged care is operating at high occupancy (around 94% of available beds) and that a substantial proportion of facilities are operating at a loss,¹¹ which may constrain providers' capacity to allocate beds to short stay respite. In this context, current funding arrangements (where respite generates lower and less predictable revenue than permanent residents) acts as a disincentive to providing respite, despite ongoing demand. This is further compounded by the additional workforce and time required to admit, assess and support people for short term stays, including settling individuals into unfamiliar environments and managing transitions in and out of care.



Proposal

Dementia Australia and Carers Australia recommend that the Department of Health, Disability and Ageing commission an independent national review of respite care services that:

1. Maps all existing respite services across aged care, disability, carer support systems, as well as mainstream health, community and social programs that may contribute to carer support, including location, capacity and availability.
2. Assesses respite demand and unmet need.
3. Identifies barriers and enablers of accessible, high-quality respite covering workforce, funding, pricing, regulation and client needs and preferences.
4. Examines accessibility for priority cohorts, including people with dementia of all ages, people in rural, regional and remote areas, First Nations and CALD communities.
5. Consults with respite service users, carers, providers, regulators and peak bodies on the experience of using respite services.
6. Provides recommendations to inform:
 - + Aged care and disability system reform
 - + National Carer Strategy implementation
 - + Care and support workforce planning
 - + Future respite service design and investment.

Conclusion

Respite is an essential support that sustains Australia's carers and enables the people they care for to remain safely at home. When respite is unavailable, inaccessible or unsuitable, carers are more likely to reach crisis points, increasing the risk of unplanned hospitalisation or earlier entry into permanent residential aged care. This places additional strain on individuals and families and drives higher costs across the health and aged care systems. A Commonwealth-funded independent review of respite care is a critical first step to improving respite policy and programs and providing better support for carers and the people they care for.

Dementia Australia and Carers Australia welcomes the opportunity to work with the Department of Health, Disability and Ageing in shaping the scope of this work.

References

1. Mylek, M. and J. Schirmer, Caring for others and yourself: The 2025 Carer Wellbeing Survey. 2024, Carers Australia,.
2. Australian Research Institute for Ageing. Respite care: Dementia care evidence theme. 2022; Available from: ➔ ariaa.org.au/knowledge-implementation-hub/dementia-care/dementia-care-evidence-themes/respice-care.
3. Australian Bureau of Statistics, Disability, Ageing and Carers, Australia: Summary of Findings. 2022, Australian Bureau of Statistics: Canberra.
4. Australian Institute of Health and Welfare. Dementia in Australia: Carers of people with dementia. 2025 2025-12-05; Available from: ➔ www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/carers-findings-survey-of-disability-ageing-carers/carers-of-people-with-dementia.
5. Carers NSW, 2024 National Carer Survey – Summary Report. 2024, Carers NSW.
6. Inspector-General of Aged Care, 2025 Progress Report on the implementation of the recommendations of the Royal Commission into Aged Care Quality and Safety: Respite care. 2025, Commonwealth of Australia: Canberra, ACT.
7. Royal Commission into Aged Care Quality Safety, A Summary of the Final Report. 2021, Royal Commission into Aged Care Quality and Safety.
8. Australian Government Department of Health and Aged Care, National Dementia Action Plan 2024–2034. 2024, Australian Government Department of Health and Aged Care.
9. Australian Government Department of Social Services, National Carer Strategy 2024–2034. 2024, Australian Government Department of Social Services.
10. Australian Government Department of Health, Disability and Ageing, Revised Explanatory Memorandum: National Disability Insurance Scheme Amendment (Securing the NDIS for Future Generations) Bill 2026. 2026, Commonwealth of Australia: Canberra, ACT.
11. StewartBrown, Aged Care Financial Performance Survey Analysis Report (December 2025): Organisation and Residential Aged Care. 2026, StewartBrown.

National Dementia Helpline

1800 100 500



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