

Senate Inquiry into aged care service delivery

A Dementia Australia Submission

August 22, 2025

Introduction

The aged care system in Australia is in a critical and necessary phase of reform. The new Aged Care Act contains the promise of rights-based care, but the operational, funding and policy arrangements needed to achieve this are yet to be realised.

The aged care system has historically been, and continues to be, under significant pressure. Australia's ageing population, increasing dementia prevalence, changing policy and regulatory environments, and financial sustainability are just some of the issues challenging the system's ability to deliver quality care to older people where, when and how they need it.

Over recent years, our stakeholders have given us consistent feedback in relation to the impacts and consequences of their inability to access appropriate aged care services and supports when they are required. The discontinuation of the Dementia and Cognition Supplement as a standalone, home care payment has imposed additional concerns about access to appropriate services for people requiring support for more complex, dementia-related care needs.

Dementia is one of the largest health, disability, and social challenges for the country. There are an estimated 433,300 people living with dementia in Australia. Without a significant intervention, the number of Australians living with dementia is predicted to nearly double to 812,000 over the next 30 years (1). There are an estimated 1.7 million Australians involved in the care and support of a person living with dementia (2). In First Nations communities, prevalence rates are higher, and the age of dementia onset is younger (3).

It is estimated that two in three people with dementia live in the community (1). They will require some form of support at some stage of the dementia trajectory. Family members and carers provide a critical source of support and care, but nobody can do it alone.

As the peak dementia advocacy body, Dementia Australia regularly surveys the community we represent on the issues that are important to them. Our submission to this Inquiry is informed by feedback from people living with dementia and current and former carers who participate in our **Dementia Advocates program**.

For this submission, we surveyed Dementia Advocates nationally about their experiences in relation to the delay in the implementation of the Support at Home program and the pause on the release of new Home Care Packages. We also asked our Client Services team for feedback about the kinds of experiences people living with dementia and carers are reporting to them through the National Dementia Helpline and other services.

While it is difficult to distinguish if the delay in implementing the Support at Home program and withholding additional Home Care Packages has exacerbated existing pressures, feedback from the respective surveys consistently highlighted that these pressures were real and had profound impacts. Survey responses indicated ongoing lack of access to aged care services in the home continues to cause significant carer stress and burnout, exacerbating poor health and wellbeing for carers and threatening the sustainability of care arrangements.

The decision to have home care support is like admitting you, as a carer, can't cope, it is a last resort. The wait only exacerbates an existing health issue for carers. ~ Former carer

For people living with dementia, the lack of access to appropriate, high-quality home care services and supports can result in reduced health and wellbeing, potentially worsening symptoms and accelerating cognitive decline.

Just to get initially assessed takes months. We are still waiting, and mum's health is declining rapidly, and she is so vulnerable. It's such a shame we don't look after our elders better and prioritise their health and wellbeing. ~ Current carer

This lack of access to home care has had two significant, nation-wide consequences. This includes unnecessarily lengthy stays in hospital and premature or unnecessary admission to hospital.

Feedback from the survey of people living with dementia and carers, and other stakeholders in the community, provides compelling testimony that many older people, including a large number living with dementia, are experiencing delayed discharge from acute care settings because they are unable to access home care packages or residential aged care places. State and Territory data supports these claims (4, 5).

The inability to access home care packages has the equally significant consequence of accelerating a decline in the health of the person living with dementia, in some cases resulting in premature admission to residential aged care or to acute care.

Dementia Australia also has significant concerns about the new Support at Home program and the changed funding model for service delivery. The discontinuation of the Dementia and Cognition Supplement is troubling because a perceived lack of supplementation may be a disincentive for home care providers to support people living with dementia. It is also not clear if the proposed access to assessment and funding for higher care needs for people living with dementia under the new higher-level classifications within Support at Home will be achievable in practice given the ongoing constraints on the system.

The new Support at Home model does not fully fund essential care services for people living with dementia care. In dementia care, there is still (and likely to be for some years) a lack of effective and widely utilised clinical treatment. This means that 'non-clinical' supportive care is the only care paradigm currently available for people living with dementia. Supportive care is a person-centred approach responding to the individual needs of each person living with dementia.

Early access to supportive care can help to delay the progression of dementia symptoms, while lack of access to these supports could increase symptom severity and the likelihood of premature entry to residential aged care. For people living with dementia, this means support for showering, eating, meal preparation, access to transport and support workers, and social engagement – all of which are vital to maintaining or strengthening cognitive function, but which the initial home care service list has identified as ‘non-clinical’ care and therefore subject to co-contributions.

There is potential for people to miss out on personal care or resort to the use of unregulated providers, increasing the risk of poor health, abuse, neglect, or exploitation. There is also a lack of training in dementia among the dementia care workforce and the specific skills needed to provide dementia care in the home including risk assessment and supporting autonomous decision-making.

Recommendations

- 1) Immediately release additional home care packages to substantially reduce the current waiting list.
- 2) Urgently work to develop solutions for older extended stay hospital patients living with dementia including by releasing home care packages targeted to this cohort to assist them to return home with appropriate support if this is clinically appropriate and is their choice.
- 3) Urgently expand access to respite care for people living with dementia, to provide support to carers experiencing stress and burnout because of not having access to home care services.
- 4) Establish a national publicly accessible, real-time dashboard detailing the state/territory numbers of patients in hospital waiting for aged care or home support, including average wait times for placement or package allocation.
- 5) ‘Non-clinical’ independence and activities of daily living for people living with a cognitive impairment should be fully funded by Government as crucial elements of supportive care for people living with dementia in both residential care and in-home support.

Consultation questions

Our submission is structured by a thematic analysis of feedback from our research in relation to specific terms of reference. It focuses on key areas and issues identified by people living with dementia, carers, and staff members. All quotes, unless otherwise indicated, are de-identified, verbatim responses from survey participants.

The impact of the delay on older Australians waiting for support at home, including unmet care needs and the wellbeing of seniors and their carers

Fear, burnout and service gaps

Feedback from people living with dementia, family members, carers, and Dementia Australia Client Services staff members indicate serious concerns about the longstanding and ongoing impacts of limited access to home care supports.

Carers have been absolutely desperate and blame themselves for the lack of care the person living with dementia needs. ~ Staff member

Staff report a significant deterioration in client wellbeing and/or carer stress levels due to delays in access to services and support.

The lengthy application process and delayed outcome of the application led to carer burnout (I needed to provide the additional support whilst working) ~ Current carer

Often when a carer reaches out for support, they are already experiencing carer stress and then when told of delays/wait periods, this compounds the level of stress. ~ Staff

Staff members report clients experience wait times of 6 to 12 months from application to services starting, which they consider unreasonable given the progressive nature of dementia. In regional areas, delays are compounded by limited provider availability.

One client has been waiting for 284 days for an interim package level 2 (awaiting level 4), called My Aged Care and was advised it would still be at least 3 months for level 2 funding. ~ Staff member

Clients who don't understand the system often get given RACF/respite codes but no home care package, so they wait another 12 to 18 months to get the support they actually wanted in the first place. ~ Staff member

The dementia has progressed beyond the assessed needs, so services are needed that were not assessed as needed 12 months ago. ~ Current carer

I requested support back at the beginning of the year and was told I would be assessed by the end of June by a provider suggested. It is now mid-August, and I am still waiting. I am a carer to my spouse and have my own health challenges and the stress has not been easy to carry as we have very little family support. ~ Carer

The consequences of these delays can include:

- Progression of dementia beyond assessed needs before services begin.
- Hospital admissions and delayed discharges.
- Earlier than necessary entry into residential aged care.
- Carers facing a decline in physical health due to prolonged, unsupported caring responsibilities.

Staff report that the lack of timely support has in some cases been distressing.

[Waiting] up to 12 months, with devastating consequences. Carer fatigue/burnout has been extreme, with major health issues arising. Increased hospital admissions. ~ Staff member

Lack of transparency in aged care services information

Our survey findings indicated that lack of accessible, clear information has potentially exacerbated existing issues in relation to access to aged care services and supports. Dementia Australia acknowledges the significant amount of work undertaken by the Department to provide accurate information, however, the amount, accuracy and reliability of information from multiple sources, may be creating confusion and disinformation to circulate.

Lack of accessibility of aged care services

Availability of, and access to, aged care supports and services has historically been more limited in regional, rural, and remote communities, and these issues persist. Staff report that clients living in rural and remote areas face longer assessment delays, fewer provider options, and significant gaps in dementia appropriate support. For people living with dementia and their carers, this can mean going without essential services or travelling long distances for basic support.

Small providers in thin markets face the highest viability concerns, which affects care availability and quality (6). When these providers close or limit services, families are left without alternatives which creates service inequities in regional and rural communities.

These concerns are even greater for First Nations people and people from culturally and linguistically diverse backgrounds where accessing dementia-appropriate assessments and culturally safe services is already a challenge. This could mean that the current delays and provider gaps increase the likelihood of people from diverse groups missing out on support.

Access to services and supports for people living in rural, regional, and remote communities, and those from First Nations and culturally and linguistically diverse communities, must be prioritised to ensure that people can access residential aged care placement or support to remain at home in a timely manner.

The impacts on aged care service providers, including on their workforce

Staff and care provision shortages, inconsistency and strain

Delays and uncertainty in relation to access have broader, systemic effects on providers and the aged care workforce in delivering dementia care. Client services staff report that their clients have experienced staff shortages, inexperienced and/or unfamiliar care workers, service cancellations, or unavailability.

One carer shared that the first three months of husband's home care package, they did not receive any services, so changed to another home care provider and it happened again. ~ Staff member

Staff report examples of providers being unable to offer dementia-specific support, with some clients struggling to find a provider at all.

Staff are often stretched; doing more than their job description because they are either understaffed or have staff that have limited dementia specific training. They need more support and funding to attract people to a career in aged care, then they'll be able to deliver the services in a prompt and professional manner. ~ Current carer

In some cases, services advertised were not delivered. Carers described months of persistent contact with My Aged Care with no outcomes, leading some to escalate to the Older Persons Advocacy Network for assistance.

Dementia Australia has advocated consistently for dementia education for all people providing care to people living with dementia. All workers providing home care must have education in dementia to ensure they are confident and competent to provide high quality dementia care and support. Dementia Australia offers a range of courses and programs, including fee-free courses, that provide relevant education in this context: **Professional Development and Training**.

The impacts on hospitals and state and territory health systems

Dementia Australia's consultations highlight that hospital pressures and delayed discharges are mounting, and there is a growing wait list for both aged care placements and home care. While it is not clear to what extent the delay to Support at Home has exacerbated this situation, a coordinated approach by the Federal and State/Territory governments is required to address this challenge.

From first-hand experience, I can say that the extraordinary delay in delivering our home care package resulted in my partner being kept in hospital for 18 weeks and then sent to an aged care facility 800kms from home due to no beds being available in our regional area as well as me having no means to support or the finances available to pay for support. My partner's home care package was delivered two days after his admission in aged care. This untimely delivery was too late for us. ~ Carer

Staff report that carers under sustained stress are more likely to experience their own health crises, leading to unplanned hospital admissions. Further, people living with dementia may be more likely to be admitted to hospital for preventable reasons, or unmanaged health needs when timely in-home support could have avoided this. Delayed or absent services mean clients cannot be discharged safely, placing further strain on hospitals.

The impacts increase the vulnerability of clients and carers to safety issues, and needs being met and also increases the likelihood of hospitalisation for the client. Carer stress is increased and therefore their ability to meet the needs of their loved one is compromised. ~ Staff member

Nationally, many older people are currently in hospital awaiting aged care services. In South Australia there are currently 291 longer stay older patients and in Queensland there are 814 (4, 5). In Western Australia, an average of 200 hospital beds daily are currently occupied by individuals assessed as needing residential or home care support (7).

Despite efforts by some State governments to develop solutions for this group, such as South Australia's hotel service providing hospital in the home for clinically stable patients, urgent action is needed to expand access to aged care. This includes releasing home care packages targeted to older people in hospitals.

As noted in the introduction, the national prevalence rates for dementia are predicted to nearly double over the next 20 years. This will exacerbate the current demands and pressures on an aged care system so longer term, preventative health measures are also required. Dementia Australia recommends governments at Federal, State and Territory level prioritise brain health promotion, including a sustained public health campaign to improve awareness about brain health across the life course to reduce the risk of developing dementia. This could contribute to a significant population level reduction in dementia, which in turn would assist in alleviating long term demands on both the aged and acute care systems.

The implementation of the single assessment system and its readiness to support people to access a timely assessment now and beyond 1 November 2025

The single assessment system was designed to simplify access and reduce delays. However, staff feedback indicates that these delays persist. This is also the case when care needs increase and a reassessment is required. The progressive and variable nature of the dementia trajectory means that support needs can change rapidly. Reassessments are required but are often delayed, resulting in increasing wait times of up to 12 months for package allocation and the provision of vital services and supports.

Advocates also expressed concerns that assessments are not always completed in a way that is supportive and understands the needs of the person living with dementia. This includes concerns in relation to the inappropriateness of conducting telehealth or phone assessments of a person living with dementia.

For many people living with dementia, cognitive changes can result in a decline in verbal fluency, difficulty processing incoming information, and reduced ability to concentrate and follow a conversation. This means communication becomes increasingly challenging for the person with dementia, and those supporting them. Telehealth and phone assessments may not be appropriate or accurate in capturing the complexity of the person's needs in this context.

Assessment was originally carried out in person however wait time was long and I cannot say it was done in a dementia friendly way. ~ Current carer

Clear guidelines, outlining when it is appropriate to conduct a telehealth or phone assessment, will improve the accurate assessment of the needs of the person living with dementia. This will ensure the person and their family members and carers receive appropriate supports and services.

We received feedback from Advocates and Client Services staff members that the new single assessment system is increasing the demand on the assessment workforce who are managing a high volume of cases with insufficient knowledge and understanding about dementia and its consequences. To ensure the appropriate and accurate assessment and support is provided, it is essential that dementia education is provided to the single assessment workforce.

Dementia Australia offers a range of courses and programs, including fee-free courses, that provide relevant education in this context: **Professional Development and Training**.

Conclusion

Our submission highlights the significant and detrimental impacts of historical and current delays in the provision of home care services and supports for people living with dementia, their family members, and carers. While it is difficult to quantify the exact degree of impact the delay in implementing the Support at Home program and the pause on the release of additional Home Care Packages has had on exacerbating existing pressures, it is clear that the pressures and constraints on the aged care system, and related demands on the acute care system, have real world consequences.

The observations we have included testify to the tangible, individual impacts for people living with dementia, their family members, and carers. The consequences are also systemic, exacerbating longstanding issues in relation to the delayed hospital discharge for older people, many of whom live with dementia, because appropriate community or residential aged care services are not available.

The impacts and consequences are detrimental for all for older people but given the unique challenges of living with dementia and the complex care and support required, these impacts are particularly concerning for people living with dementia, their families, and carers.

The downstream effects of the delay are also apparent in the potential for premature entry into residential aged care because people living with dementia are unable to access the services and supports, they require in a timely manner to continue to live in the community.

Dementia Australia strongly encourages the Inquiry Committee to consider our recommendations and welcomes the opportunity to provide more information or to discuss any of the issues raised in this submission in more detail.

The Dementia Australia policy team can be contacted at [**PolicyTeam@dementia.org.au**](mailto:PolicyTeam@dementia.org.au)

References

1. Australian Institute of Health and Welfare. Dementia in Australia. Australian Government 2024.
2. Dementia Australia. Facts and Figures 2025 [Available from: [**https://www.dementia.org.au/about-dementia/dementia-facts-and-figures**](https://www.dementia.org.au/about-dementia/dementia-facts-and-figures).
3. Australian Institute of Health and Welfare. Population Health Impacts Among First Nations People 2025 [Available from: [**https://www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/dementia-amongst-first-nations-people/population-health-impacts-dementia-first-nations**](https://www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/dementia-amongst-first-nations-people/population-health-impacts-dementia-first-nations)].
4. SA Health. Patients awaiting RACF placement 2025 [Available from:

<https://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/about+us/our+performance/racf+waiting+times>.

5. Queensland Health. Long-stay patients 2025 [Available from:

<https://www.performance.health.qld.gov.au/statewide-performance>.

6. UTS Ageing Research Collaborative. UTS Ageing Research Collaborative (UARC) submission to IHACPA Consultation on its pricing framework for Support at Home 2026-2027. Sydney: UTS; 2025.

7. Murphy R, Bidstrup E. Lack of aged care beds, home support keeping the elderly in hospital in WA. ABC News. 2025.

8. Egan C. Battle between states and Commonwealth looms as 680 NSW hospital patients wait on aged care bed. The Weekly Source. 2024.