



Office of the Inspector-General of Aged Care Review: Administration of My Aged Care

Dementia Australia Submission

June 2024

Dementia Australia

Dementia Australia is the peak dementia advocacy organisation in Australia.

Our organisation engages with people with dementia, their families and carers in our activities, planning, policy and decision-making, ensuring we capture the diversity of the living experience of dementia across Australia.

Our advocacy amplifies the voices of people living with dementia by sharing their stories and helping inform and inspire others. As the trusted source of information, education, and support services, we advocate for positive change for people living with dementia, their families and carers, and support vital research across a range of dementia-related fields.

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Dementia in Australia

Dementia is the term used to describe the symptoms of a large group of complex neurocognitive conditions which cause progressive decline in a person's functioning.

Dementia is not just memory loss - symptoms can also include changes in speech, reasoning, visuospatial abilities, emotional responses, social skills and physical functioning. There are many types of dementia, including Alzheimer's disease, vascular dementia, frontotemporal dementia and Lewy body disease.

In 2024, it is estimated there are more than 421,000 people living with all forms of dementia. This figure is projected to increase to more than 812,500 by 2054.¹

Dementia is the leading cause of disease burden among Australians aged 65 and over. Dementia is the second leading cause of death for Australians and the leading cause of death of women.²

¹ Dementia Australia (2023) Dementia Prevalence Data 2024-2054, commissioned research undertaken by the Australian Institute of Health and Welfare

² Australian Institute of Health and Welfare (2024) [Dementia in Australia](#), AIHW, Australian Government, accessed 4 June 2024.

Dementia Australia's interaction with My Aged Care

Dementia Australia provides information, support and advice to people living with dementia and carers through the National Dementia Helpline. With funding from the Department of Health and Aged Care we have established systems to receive referrals directly from My Aged Care agents to the Helpline. We continue to work with the Department to refine these systems.

Dementia Australia has previously provided bespoke training to My Aged Care staff to develop effective communication strategies to work with people living with dementia over the phone. This training was delivered with funding from the Department of Health and Aged Care.

Consultation approach

Dementia Australia undertakes systemic advocacy to improve outcomes for people living with dementia, their families and carers. We work closely with a national network of people living with dementia and carers (Dementia Advocates) and regularly receive information and advice about people's experiences of different aspects of the aged care system.

For this submission, Dementia Australia surveyed people living with dementia and carers to better understand their experiences of using My Aged Care. Below, we present the findings of our survey including statements about people's direct experiences with My Aged Care.

A variety of experiences were reported. Overall themes for negative experiences included complexity in navigating the My Aged Care systems especially for older people, time spent accessing My Aged Care, difficulties with operators or assessors, long waiting times for access to services and a lack of support in regional, remote or rural areas.

On the positive side, some respondents reported that they found My Aged Care staff helpful and empathetic. Most respondents reported that access to an assessment happened within a satisfactory timeframe, although time to access services remains a significant concern.

Survey demographics

We had 40 respondents to our survey, consisting of 37 carers and 3 people living with dementia. Thirty per cent were aged between 66 and 75, and around 38% were aged between 76 and 85. Most respondents (70%) were female. Most lived in major city areas (58%), with 40% living in a regional area, and the remainder in a remote area.

Respondents were from all states and territories other than the NT. The largest response rate was from NSW. Ten per cent of survey respondents identified as being from a culturally and linguistically diverse background, none identified as Aboriginal and/or Torres Strait Islander and around 5% identified as LGBTIQ+.

Time to receive assessment

We asked survey respondents how long it took to get confirmation that they had a booked assessment through My Aged Care. There was a mixed response, with timeframes reported

from a few days to 12 months. The most common response was between 2 and 4 weeks and there were no noticeable differences in the timeframe reported by people in major cities and regional, rural or remote areas. Around 60% of respondents accessed My Aged Care through the phone line, and 43% through the website, again with no noticeable difference by location. Only two respondents reported accessing a face-to-face centre.

Awareness

Respondents had become aware of My Aged Care in a variety of ways. These included word of mouth, friends and community networks, GP, Dementia Australia or internet research. Social media, media and advertising also featured among the responses. Most respondents indicated that they were able to find My Aged Care when they needed it, although there were some reports of difficulty, especially for people older than 80.

Expectations

When asked whether the experience of My Aged Care met their expectations, survey respondents had mixed views.

On the positive side, some respondents reported that the process was timely and helpful.

“Timely service, informed and empathetic staff, easy to access services, staff understanding rapidly changing circumstances”.

“Excellent assessment by a very proficient interviewer”.

“My husband was assessed quickly by a home visit and support was offered and available within a month”.

Others said that while the assessment process was satisfactory, there was a big delay when it came to accessing services.

“I have codes for home care and gardening but cannot get any help. Have been waiting for over one year to get help but none available”.

“The actual interaction the My Aged Care site is okay, it’s just getting access to the services that is difficult. Waiting lists, staff shortages and completing documentation make it a frustrating exercise”.

Several respondents reported negative experiences with My Aged Care.

“I was expecting the bureaucratic process to be difficult, but it was much harder to get through than I had imagine. I have spent too many hours on hold waiting to speak to people on the phone”.

“Their first visit we were not approved for services as they did not recognise my husband’s dementia as he appeared capable physically”.

“Apparent shortage and location of assessors responsible for delays”.

“Somehow it’s not fully practical or well-functioning”.

“My expectations are very low, and it has even failed to meet them”.

Barriers

Most respondents reported that there were few barriers to them accessing My Aged Care or getting an assessment. Some negative experiences were reported, that related both to waiting times, and difficulty navigating services.

“I delayed because I found it difficult to face the bureaucratic maze; because living in a rural area at the time I knew that appropriate services were not available”.

“Too many questions that are ambiguous and operators are not helpful, also long waiting time on the phone”.

“The duplication of assessments and the waiting time for a community ACAT had a negative impact on us”.

“I'll never live long enough to navigate their system”.

A small number of respondents reported that they did not access My Aged Care for an assessment, but rather had an ACAT assessment through hospital.

Assistance to use My Aged Care

Most respondents to our survey said that they did not use the assistance of a navigator, care finder or advocate to use My Aged Care. Some respondents said that they spoke to Dementia Australia for advice. A small number of respondents reported negative experiences when they tried to get assistance to use My Aged Care or demonstrated confusion about the role of care finders.

“I've heard they exist but how do you find them and how do you find one that is independent of ‘providers’ and is knowledgeable both of individual needs and the system”?

Overall experience

Our survey respondents gave a wide range of reports about their overall experience with My Aged Care. Some of the negative feedback noted that there was too much complexity in the processes, and that it took too long to get access to services. For example, respondents said that:

“It's not as easy as it needs to be. The whole process can be daunting and overwhelming at best, especially for our older generation”.

“It has been very difficult to maintain the perseverance. I can well understand why so many people give up or don't even get started”.

“It was mediocre and we were never going to get the services because of the waiting lists”.

“Once you know and understand the system and the way they operate, it is reliable and extremely useful. However, it is slow in the beginning, and they do not ever explain the full range of services available. They are also in my experience unable to respond to any kind of emergency support request in a timely manner”.

“Lack of support in country, rural and remote areas”.

“Need more staff in rural and remote areas”.

Some respondents had a more positive view, including that staff were helpful and useful:

“Very good and helpful each time I called. They were able to support me with a financial issue as well as assessment”.

“Helpful but I am relatively tech savvy”.

“All my interactions with My Aged Care on behalf of my partner were great, whether by phone or in person”.

“Much more accessible publicity is needed for carers and clients about how easy it is to contact My Aged Care. Reassurance that this service is intended to keep people out of nursing homes if at all possible”.

Recommendations

Overall, survey respondents had mixed experiences of My Aged Care, leaning towards neutral or negative experiences. Key challenges included navigating complex systems especially for older clients, and lack of service availability, especially in regional, rural and remote areas. To improve service delivery, Dementia Australia recommends that the Department of Health and Aged Care:

1. Continue to invest in initiatives which improve ease of access to My Aged Care for people living with dementia and carers.
2. Ensure that My Aged Care staff receive training in understanding dementia and in communicating and working with people living with dementia.
3. Ensure that the website and any other communication about My Aged Care services is delivered in formats that are accessible for people with a cognitive impairment.
4. Make further refinements to the service in consultation with people living with dementia and dementia carers, to improve accessibility. This includes referring to Dementia Australia’s guide to meaningful consultation with people living with dementia, families and carers is available here: [Half the Story](#).
5. Consider expansion of both access to My Aged Care and to aged care services in regional, rural and remote areas, and development of flexible service models that can meet the needs of people living with dementia and carers in these areas.

6. Continue publicity and promotion of My Aged Care to ensure that people living with dementia and carers are aware of service pathways. This should include promotion through GP clinics and community services as well as media and social media.

Dementia Australia would be pleased to work with the Department of Health and Aged Care to support further improvements to My Aged Care, such as through the delivery of a renewed bespoke training program, or engagement with people living with dementia and carers. Dementia Australia can also undertake appropriate promotion if requested to do so.

Thank you for the opportunity to share the views and experiences of people living with dementia on the My Aged Care system as part of this review. Dementia Australia would be happy to provide any further information you may need.