

Wait times for home care packages

Timely access to home care support is critical to maintaining the health and wellbeing of people with dementia, their carers and families. The current long wait times for aged care support are resulting in increased unmet care needs for people with dementia, and premature entry to residential aged care.

Reducing the wait time for home care supports and addressing the lack of home care packages must be an immediate priority for the Australian Government. Until sufficient home care packages become available, interim supports for people with dementia must be improved to ensure the changing care needs of people with dementia, their carers and families are met.

Issue

Timely access to aged care support in the home is critical to preserving an individual's independence, wellbeing and capabilities. Services provided by a home care package may include personal care, domestic assistance, food services, nursing, medication supervision, transport, home maintenance, and mobility equipment. There are four levels of Home Care Packages, ranging from basic care needs to high care needs.

People living with dementia, their carers and families often report waiting over 12 months to receive a home care package, when they are often already in an urgent state of need. Often this is an interim package at a lower level, and the wait to receive a package at the level at which they have been assessed is much longer. People also report that by the time they receive a package, the original assessment is outdated, and they require a higher level of support. The current excessive wait times for home care support mean that many people living with dementia are without the support they need to live well and as independently as possible.

“The help I needed came way too late, having applied in May 2015, she was finally granted level 4 in May 2019. As Alzheimer's is progressive, by the time the package is granted the person needs higher levels of care.” Carer

Dementia is a progressive neurodegenerative condition, and over time people will require increasing supports to remain living independently. Although the rate at which dementia progresses varies between individuals, people with dementia can progress from needing a low level home care package to a level 3 or 4 package in a matter of months.

“Because of insufficient home care assistance, as well as carer's support, in the last 3 months his dementia deteriorated a lot and so did his movements.” Carer

“There needs to be more frequent assessments, more packages made available, more services made available at each level and a person to guide users through the process. Most people have no idea what to do or what the waitlist is, they don't understand the services they need and what is available. It is quite a mess out there.” Carer

Whilst the interim services provided through the Commonwealth Home Support Programme (CHSP) are welcomed, many people with dementia, their families and carers report that this support is not enough for individuals with dementia who have increasing and complex care needs. In the absence of sufficient home care supports, individuals with dementia may experience faster cognitive and functional decline, whilst also being at increased risk of accidental harm as their carers and families face greater pressure to provide an increasing level of care.

“The long wait times significantly impacted my family. I had to give up work to care for my mother, I then became ill when the burden and worry became too much and then had to put my mother into full-time care.” Carer

- The shortage of appropriate interim and home care package supports is, in part, compounded by the lack of data available regarding the demand for services for people with dementia. With the rate of dementia rising, the need for home care packages appropriate for people living with dementia will increase significantly. Understanding the demand for services for people with dementia should be a priority for Government. Currently there is no data available about the number of people on the waiting list living with dementia applying for home care supports, or what level of support they require. This information is fundamental to the ability of government and providers to deliver sufficient services and supports for people with dementia. An ability to capture vital information will help curate services that are relevant to the growing cohort of people living with dementia.

Dementia Australia's position

People with dementia overwhelmingly report that they want to remain living at home, for as long as possible, which requires less Government funding compared to living in residential aged care. However, the ability of people with dementia to remain at home depends on the quality and availability of home care supports. The growing queue of people awaiting home care support is a marker for the increasing level of unmet needs in the community. Addressing the lack of home care packages must be an immediate priority for the Australian Government.

Government must restructure the home care package system to ensure it is responsive, flexible and eliminates the excessive wait times for people with high or complex needs. There must be a particular focus on reducing the wait time for individuals in need of high level home care packages (Packages 3 and 4) who are currently facing the longest wait for supports. Introducing a maximum wait time of three months will provide some reassurance for those who

are awaiting supports, and establish a clear expectation that those in need of home care will not be forced to wait an unlimited period of time.

Implementing a prioritisation system which supports vulnerable groups, such as individuals living alone or those who do not have the funds to support themselves, would help to reduce the acute risks to individuals who do not have access to alternate supports.

Until the wait time for home care is significantly reduced, Government must improve access to interim supports to individuals with progressive conditions, like dementia, who require increasing supports to respond to their changing care needs. An additional package of interim supports – provided at the point of applying for home care support - would help to reduce unmet care needs, in addition to easing the pressures on carers and families and preventing premature entry to residential care. This could include access to allied health and psychosocial supports to enable people living with dementia and carers to maintain their wellbeing.

Improved navigational support and communication around the assessment and home care package processes is urgently needed. Following an initial application, many people report feeling confused about how long the wait time is and where they can go to access interim supports. Appointing a consistent point of contact for applicants, with whom they can discuss the progress of their home care package, and where they can find supports appropriate for their assessed needs, is essential.