Aged Care Rules 2024 – Service List

Dementia Australia Submission October 2024

Dementia Australia appreciates the opportunity to provide feedback on the Aged Care Rules 2024 – Service List. We remain concerned that there is a lack of clarity about how the structure of services will be applied to people living with dementia, and whether the pricing model will disadvantage people living with dementia.

We also note that the proposed wording of the service definitions for in home restorative care, allied health and therapy services, nutrition support and therapeutic services for independent living is not inclusive of people living with dementia whose support needs arise from dementia symptoms.

Specifically, we are seeking clarification on the following issues and an explanation of how the Rules will be applied for people living with dementia without disadvantaging them.

1) Structure and funding of care for people living with dementia

As outlined in our Submission to the Parliamentary Inquiry into the Aged Care Act 2024 Bill, Dementia Australia is concerned that the proposed differentiation of clinical care from independence and everyday living services may inadvertently disadvantage people living with dementia.

Best practice care for people living with dementia includes both clinical services and 'non-clinical' supportive care, including activities of everyday living and independence. This means that as well as nursing or other clinical care, people living with dementia need access to assistance for activities of daily living, self-care, social support, transport, domestic assistance, therapeutic support and assistive technologies. These are all vital to maintaining independence, strengthening cognitive function, decreasing symptom severity and for those living at home, preventing premature entry to residential care.

The proposed funding model under the new Aged Care Act designates independence and everyday living services as 'non-clinical', not intended to be fully funded by government and therefore subject to means tested consumer contribution.

The Government response to the Aged Care Taskforce argues that everyday living services such as domestic assistance and gardening should attract the highest individual contribution rates because Government does not typically fund these services for people at other stages of life.

However, it is critical to understand that Government **does** fund these services for other people with a disability, based on assessed need, through the National Disability Insurance Scheme. **Dementia is a disability**, **not a normal part of ageing**. The need for funded independence and everyday living services is related to the impact of this disability on function, not because of older age. As people aged over 65 are not eligible to enter the National Disability Insurance Scheme, access to these services through the aged care system is imperative.

We believe that the proposed model may effectively disadvantage people living with dementia, who require essential supportive care services including independence and everyday living services to maintain their wellbeing and quality of life, both at home and in residential care settings.

Dementia Australia is seeking amendments to the Service List to ensure that there are mechanisms included to increase the subsidy for people living with dementia for supportive care services in the independence and everyday living categories, that are currently proposed to not be fully funded by government. This could potentially include a dementia loading type to increase the subsidy amount, eligibility for a fee reduction supplement for people living with dementia, or other mechanisms.

We are also unclear as to whether the proposed Dementia and Cognition Management service in residential clinical care is intended to replace the current Dementia and Cognition Supplement, and if so, why this service has not also been listed in the home support service types, as is currently the case.

We further note that the proposed hourly caps for services like cleaning and gardening are likely to be inappropriate for people living with dementia and other neurodegenerative diseases who rely on these services to remain living at home and whose needs increase over time with symptom progression.

2) How restorative and therapeutic care will be implemented for people living with dementia

The current service definitions for in home restorative and therapeutic care exclude people living with dementia whose needs arise from dementia symptoms. Dementia is not caused by ageing, rather it occurs because of a range of neurodegenerative diseases which progressively affect cognition and function. People living with dementia require ongoing therapeutic support to manage symptom progression and maintain independence and quality of life.

The concept of restorative care as described in the Service List, where services are provided on a short-term basis to allow an individual to reach a level of independence at which maintenance therapy will meet their needs, is not applicable to people living with dementia. People living with dementia have an ongoing need for reablement and support for independence.

Similarly, the description of allied health and therapy services as being short term, intended for the management of conditions related to age-related disability or decline and to promote independent recovery, is not applicable to people living with dementia and would potentially exclude them from eligibility for allied health therapy assistance at home. People living with dementia do not recover from the condition but require ongoing reablement services to maintain independence and function.

This also applies to the definition of nutrition supports, for which the need does not arise from age-related functional decline but through progressively worsening symptoms of dementia which can affect swallowing and independence with nutrition.

Access to diversional therapy and other therapeutic supports for independent living would also be limited for people living with dementia if the current definition is not amended, as it currently requires the service to be related to management of conditions related to age-related disability or decline.

Assistive technologies, which are vital in maintaining a range of areas of function for people living with dementia, are also classified as independence supports and therefore may be inaccessible due to lower subsidy and higher cost to the person living with dementia.

We are also concerned that time-bound access to palliative care supports is insufficient to meet the needs of a person with dementia at the end of their life. Dementia Australia is a provider of palliative care services and our experience suggests that palliative care support for people with dementia generally extends beyond 12 weeks and must provide respite support to carers.

The need for people living with dementia to have access to independence and everyday living services to maintain wellbeing is clearly illustrated by Bobby Redman, Chair of the Dementia Australia Advisory Committee in this excerpt of her evidence to the Senate Standing Committee on Community Affairs on 11 October 2024:

> “Basically, I'm here to express examples from my own experiences of the difference of regular ageing, normal ageing, to ageing with dementia and the lack of clarity between the two, or the bunching together. They're in very different spaces.
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> I've been in the aged-care system for probably about six years now. I started off on a package. I was transferred onto a level 2 program because my carer at the time felt that I was no longer safe living at home.
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> Although I don't look as if I have dementia – this is the terminology that people use all the time: we don't look any different; we don't look as if we have a disability – they thought I was at high risk and actually wanted me to go into residential care, which I'm certainly not ready for.
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> That lack of recognition at the really early stages – I think everything that's in place at the moment is looking good for people who are further down and the stereotypical people with dementia, the later stage when it's nursing care that they're looking.

For people like me – and I can't represent everybody, but I represent a lot of us. There are 80 per cent of us living in the community and many are like me, trying to live normal lives but with a lot of challenges in order to live normal lives.

For instance, our drivers licences are virtually taken away from us; our drivers licences go almost immediately on diagnosis. If not, we're put on strong restrictions pretty soon after we are diagnosed. Research is showing that we have to practice our daily activities, so activities of daily living, including being out in the community, being able to get out into the community and do the things that we need to do to keep our minds going.

In normal ageing, there are issues, sometimes, with this, but the problem is when we have an elderly couple where the person that's been the driver is the one that has the dementia. That means two people are trapped in their home. I live alone, so I'm totally reliant on public transport. Those issues make it very easy to not keep participating in life.

Activities of daily living and social engagement are not quality of life for us; they're about not degenerating. Once we don't engage, we forget how to do it and we back away from it. I'm a retired psychologist, so I've got very strong programs which are helping me to function.

Even so, we will progress very quickly, and we will cost the country a lot more because the bottom line is you will be paying more for our home support. But we will also be going into residential care much quicker because we won't continue to function. We will lose function if we don't practice it and if we're not supported to practice it.

I have one more point on the restorative care aspect. I note that that's been included. But restorative care is quite different for us, in as much as in normal ageing often there are falls, fractures and temporary injuries where the 12-week restorative care is ideal for getting people back on their feet. But for us—I now walk with a cane.

People I know are losing their voices; they're not able to swallow. So ongoing restorative care is necessary, because we're not going to get better but we need to be able to maintain our levels or, again, deteriorate very quickly. I hope that clarifies the difference.

Dementia's not just memory. For me, I don't have Alzheimer's. It's not always a memory issue. It is very much about being able to organise oneself, to do tasks and to be able to get yourself organised to get out and do things. It's organisational skills. It's sequencing. It's mobility, which deteriorates very quickly because of the neurological impacts. There are a number of factors.

Although they're not clinical, for us it's almost a clinical issue in as much as, if we don't do it, we will deteriorate very quickly”.

Dementia Australia appreciates the opportunity to comment on Service List. We look forward to ongoing discussion about how implementation of the new legislation can provide the best possible care and support to people living with dementia.

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