

## Consultation on draft lists of NDIS supports

August 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, a projected percentage change of 93%.<sup>i</sup> More than 1.6 million people in Australia are involved in the care of someone living with dementia.<sup>ii</sup>

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.<sup>iii</sup>

## Younger onset dementia

Dementia is more common in older people, but it is not a natural part of ageing and can affect people in their 30s, 40s and 50s. Dementia can occur across the lifespan and can be diagnosed in children, teenagers, and young adults. There are over 100 rare genetic conditions that can cause childhood dementia.<sup>iv</sup>

In 2024 it is estimated there are almost 29,000 people living with younger onset dementia. This figure is projected to increase to almost 41,000 by 2054.<sup>v</sup>

The misconception that dementia is a condition of old age contributes to, and exacerbates, the multiple challenges experienced by younger people with a diagnosis of dementia. People living with younger onset dementia often receive a diagnosis when they are in full-time employment and actively raising and financially supporting a family. Their experience with the condition and the kinds of support and services they might need can be different to those diagnosed with dementia at a later stage of life. Loss of income, self-esteem and perceived future purpose can pose multiple physical and psychological challenges for people with younger onset dementia and their family members and carers.

## Introduction

Dementia Australia welcomes the opportunity to provide feedback on the proposed lists of supports to be included and excluded under the National Disability Insurance Scheme (NDIS) and in particular, highlight the specific needs of people living with younger onset dementia and potential impact of the lists on this cohort.

## Services included

### Assistance in coordinating or managing life stages, transitions, and supports

The framework for support coordination may not adequately meet the needs of people living with younger onset dementia. The intention to phase out support coordinators as a participant's understanding of the NDIS increases assumes a level of cognitive stability or improvement that is not appropriate for individuals with younger onset dementia. Given the progressive nature of dementia, participants with younger onset dementia are unlikely to experience increased understanding over time but rather, will typically require ongoing, increased support to understand information and make decisions. It should not be assumed that every NDIS participant will attain independence in service navigation, and it is essential that this service remains flexible to ensure that support coordination is available as needed. Additionally, the National Disability Insurance Agency (NDIA) should ensure that there are connections to organisations such as Dementia Australia who can support people living with younger onset dementia to manage transitions and understand service options.

## Services not included

### Landline, mobile phones, and accessories

Dementia Australia is concerned about the exclusion of funding for landline, mobile phones, and related accessories. Communication difficulties are some of the earliest occurring, persistent and significant challenges that individuals with younger onset dementia experience. Specialised equipment and services, including phones and other devices with simplified interfaces or adaptive technologies, are critical for people living with younger onset dementia to promote independence, support changing communication needs, and ensure social connection and personal safety. Excluding these devices from NDIS funding could reduce the ability of people living with younger onset dementia to remain independent, connected and safe. Dementia Australia recommends that these be included as a NDIS support for people with demonstrated need and the NDIA ensures that participants are referred to organisations that support people to access appropriate communication tools.

### Smartwatches

As with access to phones and other communication devices, Smartwatches, particularly those with GPS tracking and falls detection, are important for many individuals with younger onset dementia to maintain their independence. Smartwatches and their equivalents provide a level of monitoring that can prevent serious harm or injury and support personal safety and well-being. Excluding these devices from NDIS funding overlooks their importance in managing risk and promoting independence for people living with younger onset dementia. Dementia Australia recommends that smartwatches are included as a NDIS support for people with cognitive impairment who require them to maintain safety and independence.

### Palliative care

Dementia Australia is concerned with the potential exclusion of palliative care. Palliative care is a health service but given the progressive nature of dementia and its variable trajectory, a palliative approach is an essential component of care and support for people with dementia. Feedback from stakeholders has indicated that NDIS services tend to be withdrawn once palliative care is to begin. This exclusion poses a significant risk to the continuity of care for people with younger onset dementia, who may require palliative care services alongside other disability services and supports.

There is a need to clearly define "palliative care" within the context of NDIS supports, ensuring that it refers specifically to "specialist clinical palliative care." This is crucial for distinguishing between the clinical care provided by palliative care specialists and the functional, non-clinical supports that should continue to be available through the NDIS. People with disabilities who have a life-limiting condition - whether that condition is related to their disability or not - should be supported to meet their functional, non-clinical needs concurrently with any specialist clinical services they require.

We echo the concerns raised by Palliative Care Australia, who have highlighted that too often, the NDIA withdraws disability support when a participant is classified as "palliative". This appears to stem from a misinterpretation of the National Palliative Care Strategy 2018, which defines palliative care as holistic, addressing both clinical and non-clinical needs - a definition based on the World Health Organisation's standards. However, in practice, palliative care services in Australia are resource-constrained and primarily focus on providing highly-specialised medical and allied health interventions. They do not have the capacity to deliver the non-clinical supports that many people with life-limiting conditions require, particularly those with disabilities.

We support Palliative Care Australia's call for a clearer working definition of "palliative care" in the NDIS legislation, specifically as "specialist clinical palliative care". This definition would help delineate the responsibilities of the NDIS from those of the health system, ensuring that individuals with terminal diagnoses continue to receive the functional and psychosocial supports they need. The existing carve-outs under the "Mainstream - Health" provisions, which allow for disability-related health supports that are part of a participant's daily life, are necessary but not sufficient to provide clarity on the responsibilities between the NDIS and health systems.

## Conclusion

Dementia Australia recognises the critical role that the NDIS plays in funding and supporting people with disabilities to live as well and as independently as possible, including people living with younger onset dementia. We understand the need for clear guidelines for the funding of what are regarded as important sources of support to promote wellbeing and independence. We strongly encourage the NDIS to consider the unique needs of people living with younger onset dementia in this context. Support for people with younger onset dementia must be flexible, inclusive, and responsive to the progressive and variable nature of the condition. We hope that our concerns will be considered in the finalisation of the NDIS support lists, to ensure that people living with younger onset dementia, and their family members and carers, receive the appropriate and comprehensive support they need to live as well as possible.

We welcome further opportunities to discuss any of the issues raised in the submission in more detail.

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<sup>i</sup> Dementia Australia (2023) Dementia Prevalence Data 2024-2054, commissioned research undertaken by the Australian Institute of Health and Welfare.

<sup>ii</sup> Based on Dementia Australia's analysis of the following publications - Department of Health and Aged Care, 2020 Aged Care Workforce Census Report, 2020, p. 6; Australian Institute of Health and Welfare (2022) Dementia in Australia, AIHW, Australian Government, accessed 20 January 2023

<sup>iii</sup> Australian Institute of Health and Welfare (2023) Dementia in Australia, Summary, Impact <https://www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/summary>

<sup>iv</sup> Childhood Dementia Initiative (2023) <https://www.childhooddementia.org/>

<sup>v</sup> Dementia Australia (2023) Dementia Prevalence Data 2024-2054, commissioned research undertaken by the Australian Institute of Health and Welfare.