



**Dementia
Australia™**

Proposed changes to the National Disability Insurance Scheme

- **Independent assessments and access**
- **Planning, personalised budgets and plan flexibility**

A submission to the National Disability
Insurance Agency

February 2021

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About Dementia Australia

No matter how you are impacted by dementia or who you are, Dementia Australia is here for you.

We exist to support and empower the estimated half a million Australians living with dementia and almost 1.6 million people involved in their care. Dementia is the second leading cause of death in Australia yet remains one of the most challenging and misunderstood conditions.

Founded by carers more than 35 years ago, today we are the national peak body for people impacted by dementia in Australia.

We involve people impacted by dementia and their experiences in our activities and decision-making, to make sure we are representative of the diverse range of dementia experiences across Australia. We amplify the voices of people impacted by dementia through advocating and sharing stories to help inform and inspire others.

Dementia Australia is the source of trusted information, education and support services. We advocate for positive change for people living with dementia, their families and carers, and support vital research.

We are here to support people impacted by dementia, and to enable them to live as well as possible.

Introduction

Dementia Australia welcomes the opportunity to provide a submission to the National Disability Insurance Agency (NDIA) in response to the consultation papers on independent assessments and access, and planning, personalised budgets and plan flexibility. Our submission has been developed in consultation with people living with dementia, families and carers, as well as Dementia Australia staff members.

Although we acknowledge the rationale behind the proposed changes to the National Disability Insurance Scheme (NDIS), Dementia Australia is concerned that the changes could adversely impact people living with younger onset dementia, their families and carers by replicating or exacerbating challenges that people impacted by dementia face in the current NDIS systems and processes. We advocate for the changes to be implemented in consultation with Dementia Australia and people impacted by dementia to ensure that the new assessment and planning processes appropriately support people living with younger onset dementia, their families and carers.

Summary of recommendations

- The NDIA ensures that independent assessors who will conduct assessments for people living with younger onset dementia receive dementia education and have a thorough understanding of the progressive impact of dementia on the person with a diagnosis, their family and carers.
- The NDIA fund Dementia Australia to provide pre-planning support to NDIS participants with younger onset dementia to ensure participants are well supported and prepared for their planning meetings.
- The NDIA works with Dementia Australia to ensure that the NDIS changes respond to the concerns and needs of people living with younger onset dementia, their families and carers.

Dementia in Australia

Dementia is the term used to describe the symptoms of a large group of neurocognitive diseases which cause a progressive decline in a person's functioning. Symptoms can include memory loss as well as 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.

Dementia is one of the largest health and social challenges facing Australia and the world. There are an estimated 472,000 Australians living with dementia in 2021¹ and around 1.6

¹ Dementia Australia (2018) *Dementia Prevalence Data 2018-2058*, commissioned research undertaken by NATSEM, University of Canberra

million people² involved in their care. Without a significant medical breakthrough, there will be almost 1.1 million people living with dementia by 2058.³

Dementia is a terminal condition and there is currently no cure. It is the leading cause of death of women in Australia, and the second leading cause of death overall. It is predicted to become the leading cause of death within the next five years.⁴

It is generally not well understood that dementia is a progressive cognitive disability. Dementia is the single greatest cause of disability in older Australians (those aged 65 and over) and the third leading cause of disability overall.⁵ Although dementia is commonly perceived to be an age-related illness, it is not a normal part of ageing. Dementia is more common in older people, but it can affect people in their 40s, 50s and even their 30s.⁶

The impact of younger onset dementia

Younger onset dementia describes any form of dementia diagnosed in people under the age of 65. In 2021, there are an estimated 28,300 people living with younger onset dementia in Australia. This number is expected to rise to 29,353 people by 2028 and 41,249 people by 2058.⁷

The misconception that dementia is a condition of old age contributes to, and exacerbates, multiple challenges experienced by younger people with a diagnosis of dementia. Overall, the experience for people with younger onset dementia – who often receive a diagnosis when they are in full-time employment and actively raising and financially supporting a family – is different from 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, their families and carers.

Younger onset dementia is difficult to diagnose, often taking three to five years and is under-recognised, resulting in community ignorance and stigma. This can result in delays in accessing necessary supports and also means that dementia programs, designed for the frail aged, don't fit the needs of people impacted by younger onset dementia, who are seeking to maintain active and engaged lives.

Younger onset dementia has a profound impact on individuals as well as their families, carers and friends. This cohort experience higher levels of unmet needs in many important areas of

² Based on Dementia Australia's analysis of the following publications – M.Kostas et al. (2017) *National Aged Care Workforce Census and Survey – The Aged Care Workforce*, 2016, Department of Health; Dementia Australia (2018) *Dementia Prevalence Data 2018–2058*, commissioned research undertaken by NATSEM, University of Canberra; Alzheimer's Disease International and Karolinska Institute (2018), *Global estimates of informal care*, Alzheimer's Disease International; Access Economics (2010) *Caring Places: planning for aged care and dementia 2010–2050*

³ Dementia Australia (2018) *Dementia Prevalence Data 2018-2058*, commissioned research undertaken by The National Centre for Social and Economic Modelling [NATSEM], University of Canberra

⁴ Australian Bureau of Statistics (2018) *Causes of Death, Australia, 2017* (cat. no. 3303.0)

⁵ Australian Institute of Health and Welfare (2012) *Dementia in Australia*

⁶ There are also some rare forms of childhood dementia, including Sanfilippo Syndrome, Niemann Pick Type C Disease and others.

⁷ Dementia Australia (2018) *Dementia Prevalence Data 2018-2058*, commissioned research undertaken by NATSEM, University of Canberra

life, such as socialisation, intimate relationships, communication, memory, mobility, psychological distress and needs for information.

Most people living with younger onset dementia will experience one or more of the following:

- problems with language and forgetting words;
- losing track of time and place, so they may forget whether it is morning or afternoon, or may become lost in their own street;
- showing poor judgement, so they may find it hard to drive a car or they may buy things they do not need;
- problems with abstract thinking, so they may not know what the numbers on their bank statement mean;
- losing or misplacing things regularly; and/or
- changes in mood or behaviour

The severity, type and frequency of these symptoms will get progressively worse over time, requiring an increased amount of support. Significant changes in needs can occur rapidly and without warning. People with younger onset dementia can also experience changes in personality, depression, anxiety, hallucinations and aggression.

The impact of dementia on younger people is quite different than the experience of older people with dementia. People living with younger onset dementia, their families and carers often face the following challenges:

- Impact on employment as people are usually still in the workforce and may be the primary income earner (affecting a family's finances);
- Disruptions or changes to family relationships and dynamics, especially carer 'burn out';
- Isolation and a disengagement from everyday activities long before the condition requires them to; and
- Difficulties accessing appropriate services and supports as they find themselves caught in the gaps between the disability and aged care systems.

People with younger onset dementia are required to navigate their way through multiple care systems as their dementia progresses. While people living with younger onset dementia are generally eligible to access the National Disability Insurance Scheme (NDIS), due to the progressive nature of their condition and need for increasing supports – which may not be available in the disability system – many people with younger onset dementia also require support from aged care services. As such, people with younger onset dementia are typically required to straddle both the aged care and disability systems – neither of which is currently fully equipped to respond to the complex needs of people living with younger onset dementia. Not only is it confusing to juggle two support systems, but the lack of a clear diagnosis and care pathway often results in people with younger onset dementia, their families and carers falling through the cracks.

“Review the legislative eligibility of people with younger onset dementia who, once accepted into the NDIS, should remain supported (in full or part) even if they transfer to residential aged care after they turn 65 years of age because of necessity (this is, after-all, a degenerative disease - some will have their independent living times up before others). This arbitrary "line in the sand" at 65 is cruel. Someone can go from having fantastic resources and individualised supports under the NDIS whilst living at home to being "one of a number in a group" if they have to enter age care after they are 65, with a dramatic falling off in individualised supports etc.” Carer

Experiences with the NDIS

Although there are many benefits, the NDIS does pose challenges for people living with younger onset dementia, their families and carers. For example, people living with younger onset dementia may have their initial access request denied due to a lack of underpinning evidence to support their diagnosis and/or its functional impact on their daily lives. Despite improvements made by the NDIA to streamline access and make the process more transparent/easier to understand, many people living with younger onset dementia and their families still find it ‘overwhelming’ and ‘confusing’ at times.

Over the last few years, Dementia Australia has seen a shift in the way NDIA planners and Local Area Coordinators interact with and respond to the needs of people living with younger onset dementia and their families. On many occasions our clients now report that they have had a positive planning experience and found their NDIA representative to be helpful, informative and person-centred. This is particularly evident when NDIA staff have previous experience working with people living with dementia and/or a thorough understanding of the support someone living with a progressive, complex and often unpredictable health condition may require.

However, there are still instances where clients report a starkly different experience, using phrases like ‘they didn’t listen’ or ‘they didn’t understand’. Ultimately, these experiences often result in plans that do not adequately meet the unique needs of the person with younger onset dementia and their family, leaving them at a loss as to what to do next. Where possible, Dementia Australia works with them in these situations to provide some additional support and information around the review and appeals process. In some instances, people impacted by younger onset dementia have contacted us retrospectively to report that after having their plan and/or situation reviewed they have ended up with a completely different plan that is much more reflective of their needs.

While the opportunity to have a plan reviewed and/or decision(s) appealed is a positive one, as with many parts of the NDIA, clients and families often find this process opaque and confusing, which can result in no further action from their point of view – particularly if they are unable to access adequate information and support relating to these processes. The role of the ‘pre-planner’ is more important than ever to make sure we support clients to get access to what they need.

“To date my experiences (with the NDIS) have been quite good partly due to having a Dementia Australia support person involved with me all the way from assessment to now ongoing support. There was a great deal of paperwork and expert's supporting evidence needed. I would want this to be referred to in future plan reviews or assessments. The changes to NDIS I think, will only work if dementia is properly understood. In the future I would like Dementia Australia to actually be able support my application, or others. I think Dementia Australia should be advising NDIS.” Person living with younger onset dementia

Feedback on the proposed changes to the NDIS

Independent assessments and access

While we acknowledge the rationale underpinning the introduction of independent assessments, Dementia Australia (and people impacted by dementia) have concerns about how they will be implemented. We are hopeful that independent assessments will overcome some of the access issues people living with younger onset dementia can currently face, however, the devil is in the detail and, like others in the disability sector, we are concerned about the decision to implement independent assessments prior to the pilot being completed and the outcomes publicly reported. The lack of transparency is concerning and the NDIA must ensure that communication going forward is open and timely.

People living with younger onset dementia were not included in the first phase of the pilot, hence it remains to be seen whether the independent assessment process works well for people living with younger onset dementia, their families and carers. Dementia Australia has received mixed reports from people impacted by younger onset dementia about the second phase of the pilot.

“We were part of the pilot scheme and had an independent assessment done. We were informed of the process which involved an interview process and no input from the existing team of allied health and support workers...Our experience with the pilot program was very positive and I think that a standardised approach will help those participants who do not have good advocates get a better outcome. Will also be good not using up part of the funding getting various reports from allied health professionals but they are the ones with the most knowledge about the disability and what supports will be needed to meet goals...” Carer

“One of the assessors first statements was that at some point he was going to observe me doing this ‘normal’ activity. There was no elaboration on what it might be. To my knowledge it didn’t happen as for the next two and half hours I sat in my lounge chair while he ‘asked’ questions...with no opportunity for a break or any kind...I suggested very early on that being able to read the questions on a paper format would be much easier for me and also allow for more accurate and meaningful answers but was told ‘that these questions were design so that anyone could answer them’...I had to ask many times for him to clarify what the question was asking...On several occasions he

became antagonistic because I questioned his questions.” Person living with younger onset dementia

“I only have one client who has participated in an independent assessment and their plan is yet to be reviewed following the assessment. Their feedback was that it was a very general assessment/ questionnaire that did not permit space for them to provide individualised feedback on their condition or experience.” Dementia Australia staff member

Until the results of the pilot are reported and the outcomes for people living with younger onset dementia are known, we cannot say with certainty whether the independent process and associated changes are suitable for people living with younger onset dementia, their families and carers.

In principle, independent assessments should ensure more equitable access to funding based on the participant’s functional capacity assessment while also considering their environmental and personal circumstances, such as how much informal support they have access to at any given time. Yet the outcome will be reliant on the quality of assessment tools (and appropriateness of these tools for people living with younger onset dementia) and the assessors.

“Independent assessments could potentially be a much better outcome for people with younger onset dementia compared to assessments being done by NDIS planners or local area coordinators who have shown on multiple occasions that their lack of understanding about younger onset dementia have negatively impacted the plans of people with younger onset dementia seeking to participate in the NDIS.” Dementia Australia staff member

Dementia Australia strongly recommends that assessors who assess people living with younger onset dementia must possess the qualification, skills and experience to understand the progressive and multiple impacts of dementia. Otherwise, we will continue to see eligibility and access decisions being made that negatively impact on people living with younger onset dementia.

“Above all else, (they need) a thorough understanding of younger onset dementia, and training and experience in working with such clients in order to be truly helpful to new applicants to the NDIS. Being non-judgemental and open-minded to each applicant's needs as an individual not making assumptions or applying a "one-size-fits-all" mentality. Knowledge and understanding of goal setting in context of living with dementia.” Former carer

“They will need an in-depth knowledge of dementia. They will need to be sensitive to other people's needs and forms of communication. They will need training and prior experience. They will need to have access to medical records and any previous assessments, neurological or otherwise. They will need good communication and observation skills. They will need to look for non-verbal cues and behaviours. They will need to include any carers, guardians, family, or friends either with the client or

separately. The assessment may need to be conducted over several sessions as clients' condition can vary day by day and fatigue and medications may affect condition." Former carer

In addition to having a thorough knowledge of the progression and impact of younger onset dementia, people living with dementia their families and carers have identified several traits and skills they believe assessors should possess. These include:

- Empathetic
- Good communicator
- Observant
- Patient
- Engaging

In terms of the logistical implications of conducting independent assessments for people living with younger onset dementia, Dementia Australia raises the following issues for the NDIA to consider:

- Given that it will take up to three hours to conduct the independent assessment, can people request that it is conducted over two appointments? A three-hour assessment process can be exhausting and possibly distressing for a person living with younger onset dementia.
- Can people request to be independently assessed by an assessor with relevant experience in neurologically degenerative conditions?
- Which assessment tools will be used during independent assessments for people living with younger onset dementia to ensure that the assessment is holistic and captures the full functional impact of their progressive cognitive disability?
- In what circumstances could a person living with younger onset dementia be exempt from an independent assessment? The symptoms of dementia mean that such assessments may not always be possible or appropriate. For example, a person may be in denial of their diagnosis or not understand the extent and impact of their diagnosis; the assessment process could trigger significant anxiety and exacerbate their symptoms; the assessment process could be particularly challenging for a person with no or limited informal support.

Some people living with dementia, their families and carers fear that independent assessments have been designed to minimise the number of people who can access the NDIS. These people are also fearful that the independent assessments will be a similar process to the job capacity assessments used by Centrelink to determine access to the disability support pension. These assessments have been distressing for some people with younger onset dementia who have been denied access to the disability support pension, despite having a terminal, progressive cognitive disability.

There are concerns that some people living with younger onset dementia may be deemed ineligible for an independent assessment by the NDIA as their disease has not progressed

sufficiently to be considered requiring support through the NDIS. What is the recourse for disputing this? There are also fears that people living with younger onset dementia will receive a poor outcome if an assessor deems their functional capacity not impaired enough, yet their symptoms could then progress very rapidly and they will not be able to access the support they so desperately need.

“We have all come across planners who really do not understand the nature of the various forms of dementia and who have judged our clients on how they presented on the actual day of their meeting, which of course has resulted in a plan that has been inadequate for many our clients’ needs.” Dementia Australia staff member

Linked to this are concerns about the independent assessment being conducted on a ‘good’ day and therefore not reflecting the true level of impairment. The functional capacity of a person living with dementia can fluctuate from day to day and within a day. An assessment conducted over short period of time may not adequately capture the extent of disability and impact on functional capacity. Additionally, the nature of dementia as a progressive and terminal condition must be addressed. A person with dementia could be deemed ineligible for the NDIS or be granted access but not receive an appropriate budget and plan because of the outcome of the independent assessment.

“I am concerned that should these assessments take place on a “good day” the results of the assessment will not reflect their diagnosis/functional capacity appropriately. I have seen many times reports submitted for the access process which despite the qualifications of those writing them fail to capture the fluctuating nature of dementia.” Dementia Australia staff member

“We need to know how much input our occupational therapist, carers and support workers will have in the process. My plan was reviewed last week. After 4 years on the NDIS I have still never been consulted by a planner. I’ll give you an example of this impact of dementia bias. My request for a keyless entry door using handprint was rejected as I’m expected to only leave the house with a support worker. My request for a Thermomix so I can continue to cook for the family was rejected as the support worker is supposed to cook. I was given 10 hours of exercise for the year as my family or support worker is meant to learn how to help me exercise, despite the fact that I’m only 55 and need more exercise than getting in and out of a chair.” Person living with younger dementia

Some people impacted by dementia also have concerns that independent assessments will be the only factor in determining eligibility for the NDIS and that other forms of evidence of disability (e.g. medical reports from professionals who understand dementia and the extent of the impact of dementia on the individual) will not be considered. The NDIS needs to clearly communicate the weighting that will be given to the outcome of independent assessments and the consideration (if any) given to other sources of evidence of disability and functional impairment.

There are also concerns about some of the timeframes outlined in the consultation paper, including:

- The need for clarity from the NDIA on the timeline of the steps in Figure 1 - Proposed Access and eligibility process for people aged 7 to 65 (from mid-2021). While this seems like a step in the right direction, it could potentially create significant delays (as we have seen with home care package delays for people with dementia over 65 in the aged care system)
- The need to have an independent assessment conducted every five years or as circumstances change. This could be overly burdensome/bureaucratic for people with younger onset dementia and carers as their circumstances can change very rapidly due to the progression of dementia.

Dementia Australia would welcome the opportunity for further consultation with the NDIA to ensure that our concerns are addressed, and that the independent assessment process works well for people living with younger onset dementia, their families and carers.

Planning, personalised budgets and plan flexibility

Overall, the proposed changes to the planning process, personalised budget and plan flexibility are positive. The greater flexibility in plans is especially supported.

To enable people living with younger onset dementia, their families and carers to prepare for the planning meeting, they will need information about the meeting and what to expect well in advance. This information must be tailored to the individual with dementia to ensure that they understand what is required of them and how the meeting will unfold.

“Provide information about what will be discussed. Let the participant know that they will have choices/options and that there is no coercion or pressure involved. The participant can request a guardian or carer to be present. Dates and times can be flexible.”

There are concerns that the planning meeting process still does not address the issue of NDIS participants with younger onset dementia receiving poor plans due to a lack of understanding of dementia and of goals for people with a progressive cognitive disability.

“This process doesn't allow anybody to say exactly what they need what they want to achieve. The independent assessor has more impact on the budget than the person most impacted. NDIS makes the decision on the budget without asking the person what they want and what their aims are. In this scenario, the participant has no real decisions to make, they have already been made for him/her.” Person living with younger onset dementia

“The idea of given the consumer a draft personalised budget plan is very important. It needs to made clear on this document that it is rough draft, perhaps based on limited information held/ obtained by an agency NDIS. For a constructive (less negative) meeting to be held the consumer needs time to digest the information, plan/document and prepare discussion items/ changes based on best knowledge. Appropriate support

persons for the consumer is a must. Don't rush meetings on the day and prior: give people time to work through their own issues.” Carer

Dementia Australia recommends that the NDIA provide funding for pre-planning support for NDIS participants with younger onset dementia to ensure participants are well supported and prepared for their planning meetings.

Regarding the personalised budgets, there are some concerns around budgets being informed by the independent assessment alone.

“The only thing I like about these changes, is that the budgets will be more flexible. This will be irrelevant however if insufficient money is in the budget because the independent assessor has under calculated the impact of the dementia.” Person living with younger onset dementia

In addition, the release of funding in monthly or quarterly blocks seems restrictive, particularly if there is a crisis where funding is required quickly or if participants need to access a large block of funding for other life events.

Conclusion

It is imperative that the proposed changes address the challenges people living with dementia, their families and carers currently experience with the NDIS. Dementia Australia recommends that the NDIA works with us to ensure that the concerns of people living with dementia, their families and carers are responded to and that the NDIS processes are supportive of people impacted by younger onset dementia.