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Improving the NDIS Experience

A submission from Dementia Australia

25 October 2019

About Dementia Australia

Dementia Australia (formerly known as Alzheimer's Australia) is the peak, non-profit organisation for people with dementia and their families and carers. We represent the more than 447,000 Australians living with dementia and the estimated 1.5 million Australians involved in their care.

Dementia Australia works with people impacted by dementia, all governments, and other key stakeholders to ensure that people with all forms of dementia, their families and carers are appropriately supported – at work, at home (including residential aged care) or in their local community.

Our close engagement with individuals and communities means that we are an important advocate for those impacted by dementia and we are also well placed to provide input on policy matters, identify service gaps and draw on our expertise to collaborate with a wide range of stakeholders, including researchers, technology experts and providers.

In addition to advocating for the needs of people living with all types of dementia, and for their families and carers, Dementia Australia provides support services, education and information aimed at addressing the gaps in mainstream services.

Dementia Australia is a member of Alzheimer's Disease International, the umbrella organisation of dementia associations around the world.



Contents

About Dementia Australia.....	
Executive Summary	1
Recommendations	2
Background.....	3
Key Principles	3
Access	4
Creating a plan.....	6
Using, reviewing and appealing decisions.....	8
Legislative framework	8

Executive Summary

It is estimated that there are currently around 27,000 Australians living with younger onset dementia, many of whom will rely on support through the National Disability Insurance Scheme (NDIS) to enable them and their families to live well with their diagnosis of dementia.

Dementia Australia's submission to the Review of the NDIS Act and the new NDIS Participant Service Guarantee is informed by feedback from people with younger onset dementia, their families and carers, as well as Dementia Australia staff working in the Younger Onset Dementia Program.

Broadly, people with younger onset dementia have mixed views of the NDIS; where some describe the benefits reaped from the NDIS, others have described their experiences to be *'frustrating, confusing and distressing'*. The key issues for people with younger onset dementia in their experiences with the NDIS include:

- 1. Training and education of NDIA staff.** As decision makers, it is fundamental that NDIA staff, including planners and local area coordinators, receive training and education on complex disabilities such as younger onset dementia. Dementia Australia staff and people impacted by younger onset dementia identify inconsistent dementia awareness amongst NDIA staff, which has impacted the quality of NDIS plans to meet the specific needs of people with younger onset dementia.
- 2. Collaboration between aged care and disability systems.** Most people with younger onset dementia will require supports through two separate systems – aged care (My Aged Care) and disability (NDIS). The siloed working of both of these systems creates a complicated process for people with younger onset dementia, who are often precariously placed between both systems. A partnership approach, where both systems create a streamlined pathway for accessing supports, would reduce the confusion and complex administrative burden that delays access to support for people with younger onset dementia.
- 3. Person-centred approach to NDIS planning.** Planning meetings for people with a cognitive impairment can be intense and often confusing. Tailoring NDIS meetings to ensure they enable people with a cognitive impairment to participate – for example, by reducing the length of meetings and ensuring questions are not overly complex – would represent a more person-centred approach to NDIS meetings for people with dementia.
- 4. Engagement of family and carers.** Family and carers should be encouraged to support people with dementia, where appropriate. People with dementia and their carers report overly intrusive and difficult planning meetings that exclude the involvement and support of an advocate or family member. The red tape around client involvement means that people with dementia are required to attend and be involved in their planning meetings, even if it is not their preference to do so.
- 5. Timeliness is a barrier to accessing supports.** One of the anticipated advantages of the NDIS is the ability to review and amend plans as people's needs change. However, in reality, time delays in reassessment can make these processes ineffective and impact on participant's timely access to appropriate support.

- 6. Transparency around decision making.** Greater transparency and improved communication throughout the NDIS processes is needed. Participants should be able to clearly understand why decisions about their application, plans and reviews are being made.

Recommendations

Recommendation: Given the unique challenge of navigating the disability and aged care systems, Dementia Australia recommends that a single NDIS dementia navigator be funded to assist people with a cognitive impairment access the right supports.

Recommendation: The disability and age care systems should commit to working collaboratively to create a single pathway for obtaining supports. The single pathway should remove the requirement for people with younger onset dementia to engage with dual systems in order to receive the support they require.

Recommendation: NDIA staff should actively encourage the engagement of family members and carers – where the individual has given consent to do so. Where an individual has indicated a preference for an advocate to act on their behalf, NDIA staff should honour this.

Recommendation: NDIA decisions need to be delivered in a more sensitive and transparent way, that takes into consideration the unique communication and cognitive needs of people with younger onset dementia. In addition, all participants should have easy access to a follow up contact, with whom they can discuss the rationale for a decision outcome.

Recommendation: Mandatory dementia education should be embedded into the training for all NDIA staff. If the recommendation to implement a single dementia navigator was supported, mandatory dementia education should be provided to the cohort of NDIS navigator staff.

Recommendations: The NDIS Rules for nominees need to be amended to reflect the needs of people with a cognitive impairment, who may require family and carers to act on the individual's behalf.

Recommendation: Mandatory dementia training should be reflected in the NDIS Act.

Background

Dementia is typically associated with older people – not people under the age of 65. However, whilst dementia is most commonly diagnosed in people over 65, the prevalence and impact of dementia in younger people is significant. Younger onset dementia describes any form of dementia diagnosed in people under the age of 65, and can impact people in their 50s, 40s and even their 30s.

In 2019, there are an estimated 27,247 people with younger onset dementia, with this expected to rise to 29,353 people by 2028 and 41,249 people by 2058.¹

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. Most notably, people with younger onset dementia often report difficulties accessing supports they require and finding age-appropriate services.

People living with younger onset dementia are generally eligible to receive an NDIS plan; however, due to the progressive nature of their condition, many people with younger onset dementia also require supports from aged care services. Not only is juggling two service systems confusing, it can often leave people with younger onset dementia to fall through the cracks of the disability and aged care systems, where both sectors see the other as better placed to respond.

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 and their families. Ultimately, more comprehensive, coordinated and age-appropriate support for people with younger onset dementia, their families and carers is critical.

Key Principles

All seven key principles outlined in the discussion paper are important for the National Disability Insurance Agency (NDIA) to adhere to. The following principles are particularly critical to the success of the NDIS for people with younger onset dementia.

Expert:

Greater understanding of dementia is fundamental to NDIS processes being suitable for people with younger onset dementia. In order to develop an appropriate NDIS plan, NDIA staff need to have the training and capacity to understand an individual's condition and the appropriate supports required. People with dementia typically have changing and progressive care needs which must be accounted for in their NDIS plan. If plans are not flexible, they soon become dated and no longer reflect an individual's current or future needs for care. Dementia Australia also recommends that NDIA staff receive communication training in order to better support people with cognitive impairments like dementia, who may need more specialised or tailored communication techniques to ensure their goals and support needs are captured.

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

Connected:

One of the key concerns raised by people with younger onset dementia is the lack of communication between the aged care and disability systems. Whilst people with younger onset dementia are under 65, the progressive nature of dementia often means that individuals will rely on specialist dementia supports which only exist in the aged care sector. In the absence of a partnership approach between both systems, people with younger onset dementia are regularly passed between disability and aged care systems – making it particularly confusing to access appropriate supports. In order for the NDIS to fully support the ongoing needs of a person living with younger onset dementia, they must be appropriately integrated with the aged care system.

Engaged:

Over time, people with dementia typically experience a decline in cognitive capacity, which impacts their ability to comprehend information, make informed decisions and communicate with others. To ensure the views of people with dementia are represented, Dementia Australia recommends that, where appropriate, carers and families are engaged in decision making processes. Currently, people with younger onset dementia report inconsistencies around the inclusion of family and carers, where some NDIA staff are reluctant to allow family and carers to be involved in the care planning processes – even if the individual with younger onset dementia has explicitly expressed that they want their family involved.

Decisions are made on merit:

People applying for NDIS supports are doing so because they require assistance to live well with their disability. Increased transparency around decision making, and increased sensitivity around the delivery of decisions, especially where the decision results in ineligibility for service, would reduce the negative impact of some participants' experience.

Timely:

People with a cognitive impairment typically present with a unique set symptoms, which progress and change over time. Sometimes these changes can happen quickly, and will trigger an immediate need to change an individual's care plan. Currently, one of the key barriers to the NDIS providing appropriate support to people with younger onset dementia is the lengthy wait times for initial access to supports as well as the wait for a plan review. According to the NDIA, reviews can experience delays of around 9 months – therefore creating a significant delay to individuals who require additional supports.² The wait times incurred for a review are a particularly pertinent issue for individuals with younger onset dementia, where in multiple cases, people with dementia have been advised that an individual's plan is unlikely to be reviewed before it is due to expire naturally.

Access

The need for system navigation

'Accessing the NDIS is difficult and confusing with a total lack of complete answers.'

'You receive a phone call and are told your planning meeting is in two weeks in many cases. The literally confusing amount of paperwork you have to provide most of which have no real bearing on their disability.' Person living with Younger Onset Dementia

² Commonwealth Ombudsman (2018) *Administration of reviews under the National Disability Insurance Scheme Act 2013: Report on the national disability insurance agency's handling of reviews*

Dementia Australia strongly encourages the NDIA to fund a system navigator which is specifically designed to support the needs of people with younger onset dementia. A designated team, who are sufficiently trained in dementia care, should be available to assist people with younger onset dementia through the NDIS processes. Specifically, the navigator's role would include: supporting participants to compile the relevant eligibility requirements, preparing for the planning process, and conducting appropriate planning meetings that engage people living with dementia in a tailored, effective way. The dementia navigator would also benefit from having close links to My Aged Care, so the NDIA can assist individuals to navigate between the aged care and disability systems and remove the administrative burden for people with dementia who currently have to access both systems – this is a key challenge which often delays access to support for people with younger onset dementia.

Recommendation: Given the unique challenge of navigating the disability and aged care systems, Dementia Australia recommends that a single NDIS dementia navigator be funded to assist people with a cognitive impairment to access the right supports.

Partnerships with other services

People with younger onset dementia can rely on supports from both the disability and age care systems. Many people with younger onset dementia and carers report that interacting with two separate systems is a significant barrier to accessing supports, and causes delays in accessing the supports and services they need.

Existing supports under the NDIS do not have the capacity to fully meet the needs of a person with dementia. A partnership between the NDIA and My Aged Care would ensure that the right package of supports is being provided to each individual, reduce excessive wait times for support and remove the duplication of assessment administration.

A common example raised by people with a lived experience of younger onset dementia is the challenge of obtaining an Aged Care Assessment Team (ACAT) assessment under the Aged Care system. Many people with younger onset dementia are being turned away from My Aged Care and told they can only access aged care services once they have exhausted all other options. Yet, the reality is, younger people are only accessing aged care supports because there are currently limited support options across either the disability or aged care sectors that meet their needs. For example, there are particular challenges around accessing residential care or respite care options which can provide ongoing supports that meets the unique needs of people with dementia (let alone younger onset dementia). To access aged care support, individuals end up relying on the NDIA to communicate with My Aged Care effectively and clearly about what is required from the aged care system. This imperfect process often creates a significant time delay to accessing supports. A partnership approach between the NDIA and My Aged Care would underpin more effective communication between both systems and thus make it easier for people with younger onset dementia to access aged care services when they need them.

Ultimately, identifying the interdependencies between both systems and carving out a single pathway is necessary if we want to prevent people with younger onset dementia from falling through the cracks of the disability and aged care systems.

Recommendation: The disability and age care systems should commit to working collaboratively to create a single pathway for obtaining supports. The single pathway should remove the requirement for people with younger onset dementia to engage with dual systems in order to receive the support they require.

Creating a plan

Person-centred approach to planning

'The planning questions were disorienting and no context was provided. As I have a cognitive disability, so many questions at one time are very disorienting.' Person living with Younger Onset Dementia

Reports from people with younger onset dementia and Dementia Australia staff identify inconsistencies in the quality of the NDIS planning process. Ultimately, without a mandatory requirement for training in dementia, planners do not consistently possess the necessary skills and knowledge to conduct productive planning meetings. Unlike other disabilities, dementia can impact individuals in different ways – the progression, type and severity of symptoms will vary depending on the type and stage of their dementia. A 'one-size fits all' approach to care planning simply does not work for people with dementia; support plans must be tailored to the individual and reflect each individual's goals and values. The experiences relayed to us indicate that support planning processes are not always collaborative and many planners arrive with pre-determined ideas of what is best for the client – despite not having a conversation with the individual about their preferences for support.

Conversely, where planners have an understanding of younger onset dementia, individuals have reported positive engagements with the NDIS – planners who had dementia-specific skills better understood the challenges the individual with younger onset dementia was facing, they were more able to direct individuals to effective supports and they helped construct an effective NDIS plan. Similarly, advocates have reported positive feedback about planners with specific neurological training and experience – which has supported them to develop dementia-appropriate plans. As such, when planners understand younger onset dementia, there is a marked improvement in the experience of participants, and to the effectiveness of NDIS plans in supporting people with dementia.

Engaging people with dementia in a meaningful and sensitive manner during planning meetings is central to developing person-centred plans, which reflect an individual's values and preferences. However, the experience of multiple people with younger onset dementia indicate that planning meetings can be intrusive, cause stress for the individual and are not conducive to a collaborative conversation about their care. Specifically, people with younger onset dementia have described their planning meetings to be too long, fatiguing and use overly-invasive questioning– which makes people feel uncomfortable and resistant to engage.

'Give people with cognitive issues more time to do an actual plan meeting. NDIS staff members should come out and answer questions and provide information rather than just showing up to fill out an application.'
Person living with Younger Onset Dementia

Engagement of family

'The interview was conducted with the knowledge that her neurologist, her clinical psychologist and her GP had submitted detailed reports. This was the most intrusive and humiliating interview for my wife. One has to understand that my wife had no real idea why she was being subjected to such humiliating and intrusive questions; can

you wash yourself, are you incontinent, can you toilet yourself.’ Carer of a person with Younger Onset Dementia

People with younger onset dementia and Dementia Australia staff describe the challenge of involving family members and carers to act on behalf of or assist the individual with dementia in the care planning process. Not only can it be emotionally demanding to respond to intrusive personal questions but some individuals with dementia also find it challenging to recall and report accurate information to the planners. The red tape around client involvement requires people with dementia attend and be involved in their planning meetings, even if it is not their preference to do so. For these reasons Dementia Australia promotes the inclusion and involvement of family members and carers in care planning processes – where there has been consent given to do so.

Recommendation: NDIA staff should actively encourage and support the engagement of family members and carers – where the individual has given consent to do so. Where an individual has indicated a preference for an advocate to act on their behalf, staff should honour this.

Training and Education

*‘Overall, I have found NDIA staff quite open and amenable to changes. However, the LAC had no degree of empathy, and just ‘do their own thing.’
Person living with Younger Onset Dementia.*

Underpinning many of the concerns raised by people impacted by younger onset dementia is the lack of consistency in dementia education – which is a critical to achieving high quality dementia care planning. A sufficient knowledge of dementia is key to ensuring NDIA staff are equipped to conduct planning meetings that engage the individual with dementia in an appropriate manner.

To use a practical example, individuals with younger onset dementia who are cognitively impaired often have difficulty answering detailed questions about their mental and physical capabilities. Therefore, when asked, individuals may unintentionally provide incorrect information – which planners may record as accurate information. This is not an uncommon experience for people with younger onset dementia, and is a considerable concern – especially for people without an informal advocate or who can support individuals in their planning meeting.

A single dementia navigator, which consists of staff with dementia training, would ensure planners have the right capabilities to engage people with dementia in their planning meetings and conduct dementia-friendly care planning.

Recommendation: Mandatory dementia education should be embedded into the training for all NDIA staff. If the recommendation to implement a single dementia navigator was supported, mandatory dementia education should be provided the cohort of NDIS navigator staff.

Using, reviewing and appealing decisions

Timeliness of decisions and reviews

One of the anticipated advantages of the NDIS processes is the opportunity for participants to amend or review their NDIS plan. In theory, this enables individuals to amend their plan and access additional supports as people's needs change. This is a particularly welcomed feature for people living with dementia, whose progressive condition often requires a change to the level and types of support they receive. However, people report that outcomes for reviews often take too long and the review process can be overly complex for participants to comprehend. We have also heard reports of plans expiring before reviews have been processed. Ultimately, the review process is not working as effectively as it should to enable participants to amend their plans in accords with their changing needs.

Transparency around decision making

Decisions around NDIS plans can be a considerable source of distress for participants, especially when people who have applied for supports are told they are not eligible. Making this situation more frustrating is the template approach to delivering decisions and a lack of regular updates about applications. A common approach reported is for the NDIA to send participants a letter stating the legislative reason for their application being declined – without prior communication and little opportunities for participants to follow up. Improved clarity around decision making, perhaps through a face-to-face meeting, phone call or more detailed description would alleviate the frustration experienced by many of our advocates.

Recommendation: NDIA decisions need to be delivered in a more sensitive and transparent way, that takes into consideration the unique communication and cognitive needs of people with younger onset dementia. In addition, all participants should have easy access to a follow up contact, with whom they can discuss the rationale for a decision outcome.

Legislative framework

'I was advised that the person with dementia would have to answer a series of questions. I advised the person that my wife would find that a significant challenge and would be unlikely to be able to answer the questions accurately. I asked for the questions and was told I could not have them... After a vigorous discussion I was given all the questions but advised I could not prompt my wife because that was in breach of the Act.' Carer of a person with Younger Onset Dementia

Whilst the NDIS Act includes provisions to allow family members or carers to be engaged in NDIS processes, in practice family and carers often feel restricted from engaging in meetings. Specifically, some advocates described planners as reluctant to allow family members to respond to questions – therefore pressing the individual with dementia to answer, even when they may not have cognitive capacity to do so. Principle F (i), under the NDIS Rules for nominees sets out that, even if a participant has a nominee, participants should be involved in decision-making, including decisions for themselves, to the extent possible. In reality, this provision results in planners putting pressure on people with dementia to respond, which can result in inaccurate information being recorded or people with dementia becoming distressed by intrusive or confusing interviews. Ultimately, whilst it is important that the NDIS Act recognises the importance of NDIS plans reflecting the views and wishes of the participant, the Act also needs to recognise that engagement of family and

carers can be critical to achieving this – especially for people with a cognitive impairment who may be unable to recall information accurately by themselves.

Recommendations: The NDIS Rules for nominees need to be amended to reflect the needs of people with a cognitive impairment who may require family and carers to act on the individual's behalf.

Dementia education is a critical enabler to effective NDIS planning and the experiences of participants. However, current legislation does not set out training requirements for planners or local area coordinators. Reports from people with younger onset dementia, families, carers and Dementia Australia staff identify the positive impact of dementia education on the experience of people with younger onset dementia and the resulting effectiveness of their NDIS plans. Ultimately, by ensuring NDIA staff receive mandatory education on complex conditions such as younger onset dementia, planners and coordinators will be better equipped to advise on NDIS plans that address the current and future complex needs of people with dementia and conduct appropriately tailored planning meetings.

Recommendation: Mandatory dementia training should be reflected in the NDIS Act.