Foundational Supports

December 2024

Dementia Australia

Dementia Australia is the peak dementia advocacy organisation in Australia. We support and empower the more than 421,000 Australians living with dementia and more than 1.6 million people involved in their care. Dementia is the second leading cause of death in Australia, yet it remains one of the most challenging and misunderstood conditions. Founded by carers more than 35 years ago, 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 lived 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 neurocognitive disorders which cause a progressive decline in a person's functioning. It is one of the largest health and social challenges facing Australia and the world. There are estimated to be more than 421,000 Australians currently living with dementia and more than 1.6 million people involved in their care. Without a significant medical breakthrough, it is estimated that there will be over 812,500 living with dementia by 2054.[1]

Younger onset dementia

Although it is more common in older people, dementia is not a natural part of ageing and it affects people in their 40s, 50s and even 30s. 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

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[1] Dementia Australia (2023) Dementia Prevalence Data 2024-2054, commissioned research undertaken by the Australian Institute of Health and Welfare

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.

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.[2]

It is now also recognised that dementia affects individuals across the lifespan including children, teenagers, and young adults. There are over 100 rare genetic conditions that can cause childhood dementia.[3]

Some people living with younger onset dementia and families of children living with dementia rely on support through the NDIS to enable them and their families to live well with their diagnosis of dementia. Broadly, people impacted by 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’.

Recommendations

- Fund a ‘Specialist Dementia Navigator’
- Provide dementia-specific training for all professionals who interact with individuals with younger onset dementia, including disability sector staff, NDIS staff and allied health workers
- Improve dementia-specific capacity-building supports
- Increase support for carers of people with younger onset dementia
- Co-design foundational supports with people with lived experience of dementia
- Expand peer support and community inclusion initiatives

Introduction

Dementia Australia welcomes the opportunity to contribute to Department of Social Services’ consultation on the development of foundational supports. The development of suitable foundational supports for individuals living with younger onset dementia and their carers is essential, as this group faces significant barriers in accessing and navigating services. This submission is informed by feedback from client services staff at Dementia Australia and people living with younger onset dementia and their carers who are a part of our **Dementia Advocates Program**. Feedback from our consultation highlights the need to improve access to information, appropriate services for younger onset dementia and collaboration across sectors.

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[2] Dementia Australia (2023) Dementia Prevalence Data 2024-2054, commissioned research undertaken by the Australian Institute of Health and Welfare.
[3] Childhood Dementia Initiative (2024). https://www.childhooddementia.org/.

Inadequate access to information and support

Dementia Australia staff and people living with dementia and their carers have consistently raised how difficult it is to find accurate, up-to-date information about available supports for younger onset dementia within the disability service system. Additionally, many individuals with younger onset dementia and their carers report feeling overwhelmed by the lack of a clear entry point into the support system. Without a centralised resource or knowledgeable contact person, they are left navigating themselves or by those who lack dementia-specific knowledge. This can delay access to essential services and/or lead them to ones that are inappropriate.

In our survey of people living with younger onset dementia and their carers most respondents indicated that it is difficult to find information about services and supports for people with younger onset dementia. In asking people living with dementia and their carers what should be prioritised in the development of foundational supports, 100 per cent of survey respondents prioritised more transparent and accessible information on available supports.

> *“It is hard to even work out what services and supports I need let alone find someone to provide advice”. Carer*
>
> *“I find it challenging to locate information about services and supports for people with younger onset dementia. What would really help is having a centralized online hub where I could easily access up-to-date listings of services and resources specific to younger onset dementia, complete with contact details and clear instructions on how to access them.” Carer*

Specialist Dementia Navigator

One of the main concerns for people living with dementia and their carers is not knowing where to begin to find supports and not knowing where to go find out what’s available. Having a centralised reference point for younger onset dementia-specific services and support options would improve the confusion around locating information and supports. In our survey to people living with dementia and their carers, most respondents identified Dementia Australia as their main source of information and advice about the services and supports that they need, reflecting the organisation’s trusted role in providing reliable information and guidance. Additionally, Dementia Australia's Client Services survey reflects that 98% of clients agreed they felt listened to, 98% agreed that their particular needs were understood, 97% agreed that Dementia Australia followed through on commitments, and 98% stated they would contact the organisation again if needed.

The Department of Social Services can support and direct people to the most appropriate services locally by funding a Specialist Dementia Navigator role through Dementia Australia. Funding a specialist navigator role would improve access to supports for people with younger onset dementia and their carers by ensuring they understand and can access the full spectrum of services available to them. This would reduce system confusion by clarifying the distinction between NDIS-funded and non-NDIS supports. This role would also provide responsive support by addressing individuals' changing needs, helping to prevent crises and unnecessary hospitalisations. Additionally, it would enhance system efficiency by bridging gaps between health, aged care, and disability sectors, improving coordination of efforts. This would ensure people with younger onset dementia and their carers receive the guidance they need to navigate complex systems.

> *"Information and help [to be made] more accessible before diagnosis. Information and support to navigate the health and medical systems, and to understand legal and financial impacts of diagnosis as well as future care." Carer*

> *"Having access to dedicated helplines with trained staff who can offer personalized guidance would make everything feel more manageable. It would be helpful to have more localized information that points to nearby services and support. Carer*

> *"To have someone allocated to me who could explain what is available and what might be useful for me." Person living with dementia*

Dementia-specific training

Both staff and advocates emphasised that many disability service providers lack knowledge of younger onset dementia. There is a need for dementia-specific training for all providers working in this space, particularly those in allied health. Post-diagnostic support pathways could also be improved by ensuring GPs are aware of dementia-specific supports and services.

> *"Current services do not understand younger onset dementia well enough and can make inappropriate recommendations as well as being unaware of the degenerative nature of the disease which can limit ability to follow up." Dementia Australia Staff*

Capacity building supports

Given the progressive nature of dementia, carers, those living with younger onset dementia and Dementia Australia staff have expressed that capacity-building and self-advocacy supports need to be adapted specifically for dementia.

At present people living with dementia and their carers are mostly unaware of capacity-building supports for younger onset dementia. They have suggested that capacity-building supports for people with younger onset dementia can be enhanced through targeted training programs, including practical skills, advocacy techniques, and navigation of support systems, while ensuring cultural appropriateness. Targeted resources focused on inclusivity, improved digital literacy tools, and stronger collaborations between community organisations and healthcare providers would help to ensure equitable access to supports, maintain independence, and strengthen community connections.

> *"Comprehensive training programs tailored to the unique challenges faced by caregivers and individuals dealing with younger onset dementia would be invaluable. These programs should include practical skills, education on navigating support systems, and effective advocacy techniques, also needs to be culturally appropriate." Carer*

> *"Establishing stronger collaborations between community organizations and healthcare providers would allow for more seamless communication and support. This could ensure that I am not only aware of available resources but also confident in using them to maintain my independence and stay actively connected with my community."* Carer

Peer support and community inclusion

People living with dementia and their carers highlighted the importance of social connection, peer support, and community inclusion as critical for reducing isolation and building community among people with younger onset dementia and their carers. Dementia Australia's services, such as carer support programs, post-diagnostic support programs, and Connecting Peers, play a significant role in building capacity and fostering connections for people living with dementia and their carers, empowering them to navigate challenges and maintain social inclusion. Having accessible and welcoming community spaces, along with tailored community engagement opportunities, was highlighted in our survey results to improve social connection among people living with dementia. This is particularly important for Aboriginal and Torres Strait Islanders, and individuals from diverse cultural backgrounds, who often face additional barriers to accessing inclusive support, and for those living in regional, rural, and remote areas, where isolation is compounded by geographic distance and limited services.

> *"As a carer of a loved one with dementia - networking and informal support through linkages with other carers who have similar care responsibilities, in particular of a younger person with dementia are invaluable."* Carer

> *"Community outreach programs like workshops and talks would also be beneficial, as would resources/workshops that are culturally tailored to different backgrounds"* Carer

Enhanced support for carers

Carers and families play an essential role in supporting individuals with younger onset dementia, yet their own needs often go unmet. Staff and advocates highlighted that greater support for informal carers is essential, including educational programs on dementia, improved linkages to community resources, and more funding for training carers. While Dementia Australia provides support to this cohort, referral pathways post diagnosis need to be streamlined to ensure people know where and how to access services and resources.

> *"A person with younger onset dementia often has a loved one/loved ones who support them as familiar carers. These carers are often invisible in the mix of services provided for people with dementia at all levels. A greater focus needs to be on supporting carers who do all the work of services who often end up with significant health issues of their own because of the nature of their care work."* Carer

Consulting with people with lived experience

Dementia Australia recommends that the design of foundational supports should directly involve people with dementia, ensuring they are aligned with their needs. ‘Half the story’ is a guide to meaningful consultation with people living with dementia, families, and carers and can provide a useful tool when consulting consumers. Half the story can be found **here**. It is important to ensure that people with lived/living experience are given the opportunity to provide input and have their voices heard.

Conclusion

We thank the Department of Social Services for considering this submission and would welcome any further opportunities for consultation.