

AUSTRALIAN  
**YOD-SIG**

Young Onset Dementia  
Special Interest Group

# JOINT SOLUTIONS SUMMARY REPORT

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Developed and prepared for the Young People in Nursing Homes Alliance

**Associate Professor Samantha Loi**

**Dr Monica Cations**

**Dr Clare Beard**

**Dr Priscilla Tjokrowijoto**

(on behalf of the YOD-SIG leadership group)

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This report was commissioned by the Commonwealth Government, Department of Social Services



## **Summary report:**

This report summarises the Joint Solutions report of the Young-Onset Dementia Pathways to Care: gaps, barriers, positives and opportunities.

The summary report presents key findings in a more accessible format.

In this summary report, YOD means young-onset dementia.

# ABOUT THE PROJECT

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Young-onset dementia (YOD) affects people under the age of 65.

In Australia, 27,800 people are living with YOD.



There are no clear guidelines in Australia for services for people with YOD and their families, both before and after they get diagnosed.



In mid-2023, the Young People in Nursing Homes National Alliance (YPINHNA) formed a Consortium group.

The Consortium received Government funding to develop a pathway of care for people with YOD.



The pathway of care will cover everything from diagnosis to end-of-life care.

The pathway will outline services that should be available for people with YOD and their caregivers.

## **The Consortium includes:**

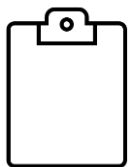
Young People in Nursing Homes Alliance (YPINHNA)  
Eastern Cognitive Disorders Clinic (ECDC)  
Young Onset Dementia Special Interest Group (YOD-SIG),

and

Dementia Australia (DA)

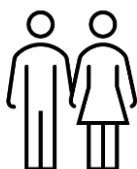
# WHAT WE DID

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A national survey was distributed across Australia. We then held a series of focus groups.

We heard from:



### **People living with YOD and their caregivers.**

In this report, the term “caregivers” refers to informal and unpaid people who care for someone with YOD, usually family members.



### **Clinicians working with people with YOD.**

Clinicians included general practitioners (GPs), medical specialists, nurses, and allied health professionals.



### **Community service workers.**

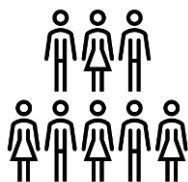
Community service workers included support coordinators, service providers and support workers.

Community service workers worked within the National Disability Insurance Scheme (NDIS), health, and/or aged care services.

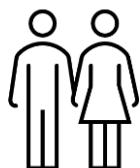
# SUMMARY OF FINDINGS

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**313** people participated and shared their perspectives and experiences:



- 33 were people with young-onset dementia
- 105 were caregivers
- 93 were clinicians
- 82 were community service workers



- 26% were male
- 74% were female



- More than 90% were Caucasian



- 68% lived in a metropolitan area

The findings are divided into three sections:

- 1.** Before diagnosis;
- 2.** Diagnosis; and
- 3.** After diagnosis, including the National Disability Insurance Scheme (NDIS).

The summary report concludes with a list of key recommendations for a Pathway of Care.

# BEFORE DIAGNOSIS

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- Specialists such as neurologists, geriatricians, and clinicians working in dementia/memory services are confident in diagnosing young-onset dementia.
- The diagnosis process includes the doctor asking many questions about the person's health and changes they have noticed. Diagnosis may involve a cognitive screening test, a neurological examination, and an MRI scan.
- Many people are diagnosed within 12 months after seeing their GP about their symptoms.
- GPs can have difficulty recognising symptoms of young-onset dementia, especially when symptoms resemble those of mental illness.
- About half of people were referred to YOD specialists or a dementia/memory service. These referrals support more timely diagnosis.
- There are barriers to accessing some diagnostic investigations such as functional brain imaging, neuropsychological assessment, and lumbar punctures. Barriers include availability, waitlists, cost, and concern about what is involved.
- Low public awareness of YOD can contribute to delays in seeking help.

## WHAT PEOPLE TOLD US

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*I took her to the GP... and I said I'm worried about her memory and whatever. And his comment, 'Well, you get a little bit older. People get a little bit forgetful,' and I had to really push him.*

*I knew I had symptoms for some time. But symptoms I considered of probably just getting old and being a bit tired at work.*

*To be honest, my partner noticed the things with memory initially, and then my kids, and then I noticed some issues with memory, but I had a lot of anxiety as well, and so I just attributed [them] to that. And it wasn't until my mental health improved and I thought, oh, wait a second, the memory stuff feels like it's actually, probably getting worse, if anything.*

*I believe that for me, having longstanding mental illness was a barrier. I know that diagnostically my symptoms cannot be attributed to mental illness alone. Health professionals sometimes don't look past the mental illness, as was in the case of the first neurologist who was dismissive of my concerns.*

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## Key targets for improvement

- ❖ **Education for health professionals.** Education and training are needed to help health professionals recognise the signs and symptoms of young-onset dementia. GPs play an important role in recognising symptoms and referring to the right specialist for diagnosis.
- ❖ **Public awareness.** Many people don't realise that dementia can affect younger people. Public education is needed to help understand YOD and reduce stigma.
- ❖ **Access to YOD specialists.** People with YOD must have access to YOD specialists to support timely diagnosis. YOD specialists also provide access to appropriate information and support. People with YOD in regional, rural, and remote areas of Australia especially need better ways of reaching specialist services.
- ❖ **Costs of tests.** Some of the tests needed for a diagnosis of YOD are expensive. Cost can be a barrier to timely diagnosis. Medicare rebates or funding mechanisms are needed.

# DIAGNOSIS

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- A timely diagnosis of YOD is important. Timely diagnosis supports understanding, future planning, and accessing appropriate services.
- Specialists and clinicians feel comfortable giving a diagnosis; however, they rarely have sufficient time to offer the support people with YOD and their caregivers need when given the diagnosis.
- The diagnosis was often communicated quickly once the assessments were completed. Most people with YOD and their caregivers were provided with detailed information about the type of dementia they were diagnosed with.
- Many people with YOD were not offered follow-up appointments where they could ask further questions.
- People with YOD and their caregivers seek information that meet their needs. There is a need for better ways to access and provide this information.
- People with YOD and their caregivers require different information at different times. Health professionals should be flexible and responsive.
- Emotional support, like counselling, should be offered when people receive the diagnosis. This should be flexible to respond to people's needs and concerns.

## WHAT PEOPLE TOLD US

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*My brother had been showing signs of dementia for probably three or four years before the diagnosis, and it was only that his work forced him to go and see a doctor that we got the diagnosis. And he was actually relieved. It changed his anger management, his temper, cause things were happening to him that he couldn't explain or understand. So suddenly he had an explanation for it.*

*The dementia word hit me like a ton of bricks... I felt very, very alone and very, very unsupported at that point.*

*First of all, you go through the denial, the bargaining and all of that. I went through all of that. I'd never really got[ten] into the acceptance probably until a couple of years later.*

*We spend a lot of time navigating grief with not only the person with dementia, but also their primary carer and their family because most of them are younger, they're working full time. There's huge financial loss. There's so many losses that occur within this grief process.*

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## Key targets for improvement

- ❖ **How the diagnosis is provided.** Health professionals need to show empathy and consider the needs of the entire family when providing a diagnosis of YOD.
- ❖ **Information about YOD.** People with YOD need specific information about their diagnosis and type of dementia. Information needs to be clear and useful. A national website is needed to help people access the information they need, when they need it.
- ❖ **Pathways and policies.** Health professionals require pathways and guidelines to follow. Pathways would help them know when and where to refer, including for services like genetic testing, mental health support, family counselling, personal care, and practical assistance.
- ❖ **Follow-up appointments with specialists and GPs.** Follow-up appointments are crucial for monitoring progress and allowing people to ask further questions about their diagnosis and the services available.

# AFTER DIAGNOSIS

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- Support workers want to know more about YOD to provide better support and assistance in the community.
- Families find it helpful to contact Dementia Support Australia to help them respond to changes in behaviour.
- People with YOD and their caregivers value emotional and psychological support. Emotional support must be timely and provided by people who know about YOD.
- Emotional support should be provided to caregivers and families, including young children of people with YOD.
- Information for people with YOD and their families must be easily available and accessible when needed.
- People with YOD and their caregivers living in regional, rural and remote areas have difficulty accessing appropriate services after diagnosis. Creative strategies are needed to improve access.
- The support and services for people with YOD must be tailored to and appropriate for their younger age and stage of life. For example, many people with YOD are still working at the time of diagnosis.

## WHAT PEOPLE TOLD US

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*My wife thinks that when you get your diagnosis you should be linked straight to a breast care style nurse who can spend time walking you and your family through your diagnosis (especially teenagers and young adults), services available in your area, and things that need to be done.*

*A care pathway and plan should be formally instigated upon formal diagnosis, which is centrally coordinated and managed across both clinical, allied health, family and support workers.*

*We had the benefit of my aunt, my mum's sister, who was a nurse – who sort of had some of the vocabulary and was able to help direct us to some resources that helped educate us a little bit.*

*We have OT and speech therapy support. But we had to find it ourselves.*

*I found with all the advocacy work that I do and that others here do too, it's really helped keep me active and I think it's probably done a bit of the retraining of the brain*

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## Key targets for improvement

- ❖ **Coordination and navigation.** A key person should be appointed to help people with YOD find and access the services they need. This should happen before they apply to the NDIS to help navigate the system.
- ❖ **Range of YOD-specific services.** People with YOD need tailored and appropriate services delivered by people trained in YOD. These services must be responsive to changing needs over time. Telehealth and online programs are needed so everyone can access support groups and get the information and help they need.
- ❖ **Directory of YOD-specific services.** A directory of YOD-specific services is needed across states and territories to support service access and navigation.
- ❖ **Increase available psychological support** for people with YOD, their caregivers, and their children. There is little support for available for children who has a parent with YOD. This should be improved.

# NATIONAL DISABILITY INSURANCE SCHEME

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- The NDIS is available to people with YOD if they receive a diagnosis before the age of 65.
- Some people with YOD have managed to access NDIS funds within 6 to 12 months of diagnosis. Other people with YOD have found applying for NDIS funds very difficult. The NDIS application requires a lot of information and supporting evidence that can take time and money to gather.
- People with YOD, caregivers, and clinicians were concerned about the inconsistency and inequity of NDIS funding. NDIS funds vary across people with YOD, even when their situations and needs are similar. NDIS funding does not always keep up with a person's changing needs over time, requiring ongoing advocacy.
- People with YOD and their caregivers are generally very satisfied with support coordination using NDIS funds.
- Many people, including specialists, are unaware of eligibility for the NDIS and how to apply for NDIS.
- YOD-specific support coordination and help to navigate the NDIS is needed.



## WHAT PEOPLE TOLD US

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*Took 6 months for them to agree that I had enough evidence. Just to submit an application. Now I have to wait up to 6 months for it to be processed. That is 12 months after my OT and doctor said I need services.*

*Absolute nightmare! Even with the support of a specialist in the area and a host of relevant reports from everyone from the Neurologist through to Occupational Therapist, I **still** do not have adequate funding.*

*The NDIS is absolutely brilliant. And we're just so lucky if we're able to get onto it. I mean, you know, I can get all my neurophysiology, things like that... so it's unlimited.*

*Support workers that know me so well that they are more friends than acquaintances, and are very helpful and respectful.*

*I have physiotherapy, carers taking me to activities... Respite to give my wife time without worrying about me.*

*The need for frequent 'Change-of-Circumstance' paperwork is stressful, time consuming, and ongoing.*

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## Key targets for improvement

- ❖ **Age-appropriate NDIS services.** More YOD-specific and NDIS funded services are needed, including day programs, respite services, and long-term accommodation options. These services must be age appropriate.
- ❖ **Directory of community providers.** A comprehensive directory of YOD-specific service providers is needed across states and territories, including allied health providers.
- ❖ **Consistent and fair funding allocation for people in the NDIS.** People with YOD must be assured equity and fairness when accessing NDIS funds. Service providers need to communicate and work together in a more coordinated way.
- ❖ **Clarify the services** accessible through the NDIS to ensure consistent and streamlined funding allocations.

## RECOMMENDATIONS FROM THE JOINT SOLUTIONS YOUNG-ONSET DEMENTIA PROJECT



A key person to find the services people need after diagnosis



Easier access to services, no matter where people live



A dedicated website that offers information and support



A communication tool for everyone involved in the person's care



Help to apply for the NDIS and other support services



More age-appropriate day programs and housing options



Better programs and services for people from different cultures and backgrounds



Better public awareness about young-onset dementia to reduce stigma, including a national awareness day