

# Younger onset dementia and the NDIS



This booklet features information on younger onset dementia and accessing the National Disability Insurance Scheme (NDIS). Please read and share it with your family, friends and carers. The information in this booklet has been based on input and discussions with people impacted by dementia.

We acknowledge and are grateful for each contributor generously sharing their time, experience and knowledge.

It is important to remember everyone living with dementia is unique. The content in this booklet is general in nature and we recommend you seek professional advice in relation to any specific concerns or issues you may have.

**For further information and enquiries please contact:**

National Dementia Helpline  
**1800 100 500**

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Find us online  
**dementia.org.au**

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# Is this booklet for you?

If you, a friend or family member has younger onset dementia, this booklet is for you. The National Disability Insurance Scheme (NDIS) is a scheme that provides funding for people under 65 with a permanent and significant disability. People with younger onset dementia may be eligible to receive NDIS funding.

This guide may provide you with information, advice and guidance to help you apply for the NDIS, and to prepare for your NDIS planning meeting to develop your NDIS plan.

It may also help you to better understand the benefits of NDIS, and how to access the services and supports you need to achieve your goals.



# What is younger onset dementia?

Younger onset dementia describes any form of dementia diagnosed in people under the age of 65. While less common, it can be diagnosed in people in their fifties, forties and even thirties. In 2019, approximately 27,247<sup>1</sup> Australians were living with younger onset dementia.

Dementia is the catch-all term for a large group of cognitive illnesses and conditions, which cause a progressive decline in mental functioning. You can have one or more types of dementia.

People with dementia may have a loss of:

- memory
- intellect
- rationality
- social skills
- ‘normal’ emotional reactions
- speech and behavioural changes.

For more information, resources and support, visit our younger onset dementia hub:

**[yod.dementia.org.au](https://yod.dementia.org.au)**



# What is the National Disability Insurance Scheme (NDIS)?

The National Disability Insurance Scheme (NDIS) is a Commonwealth Government program that provides funding for people under the age of 65 with a permanent and significant disability. If you or someone you care for has younger onset dementia, the NDIS could be a great help. It could connect people with dementia to reasonable and necessary supports and services to help them in their daily life, connect with their community and achieve their goals.

**Tip** – The amount of support you receive from the NDIS is based on your specific needs, not on your income or assets. It is also not affected by a Disability Support Pension.

# Am I eligible for the NDIS?

You may be eligible for the NDIS if you meet these requirements:

- You have younger onset dementia, and it significantly affects your ability to take part in everyday activities.
- You are aged under 65 years when you register for the NDIS.
- You live in Australia.
- You are an Australian citizen, or have Australian residency.

The NDIS has three useful booklets that can help you learn more about the NDIS:

- Understanding the NDIS
- Planning
- Using your NDIS Plan

You can find them on the NDIS website  
**[ndis.gov.au](https://www.ndis.gov.au)**



# How can the NDIS help me?

Being diagnosed with younger onset dementia is challenging. Having dementia will change your life in many ways due to the way it affects the brain. But you don't have to navigate these changes alone.

The NDIS can provide you with funding to access services and supports that help you live well, maintain your health, and stay connected with your friends and community.



## **Benefits of applying for an NDIS plan**

### **Help with everyday tasks**

NDIS can fund in-home support and assistance to help you manage daily tasks at home. This may include:

- showering
- dressing
- cooking assistance
- medication management
- cleaning
- gardening
- shopping assistance.

### **Dementia-friendly home environment**

NDIS can fund home modifications and assistive technology products to make your home feel safe and secure, and help you maintain a daily routine.

### **Connect with community and social activities**

NDIS can provide funding to help you maintain social relationships and community support to help you live well. This may include:

- transport
- assistance to participate in group activities
- visits to a day centre to enjoy social support groups and activities with other people living with younger onset dementia.

## Help to look after your heart, body and brain

NDIS can provide funding to help you look after your heart, body and brain. This may include:

- physiotherapy
- speech pathology
- occupational therapy
- dietary advice
- 1-1 support while exercising
- carers to accompany you on walks or exercise classes.

As your circumstances change, you can apply to have your plan reviewed and adjusted accordingly.

**Tip** – The NDIS provides funding, information and connections to supports and services you need to live well.





# Part one – Apply for NDIS funding

As you work through your NDIS application process, you may feel a range of emotions. For example, you may feel frustrated or angry when talking about things in your life that may have become more challenging recently. Or if you are a family member, you might feel upset describing how things have changed in the person with younger onset dementia.

Dementia Australia has trained counsellors that can help you to work through these emotions. If you would like further information about this service, please call our **National Dementia Helpline** on **1800 100 500**.

## How do I access the NDIS?

Use the step-by-step checklist on the next page as instructions to access the NDIS.

## Younger onset dementia and NDIS checklist

Activity	Date completed	Outcome
<b>Step 1</b> <ul style="list-style-type: none"> <li>Assess your eligibility to receive NDIS funding</li> <li>Visit the '<b>Am I Eligible?</b>' section of the NDIS website <b><a href="https://www.ndis.gov.au/applying-access-ndis/am-i-eligible">ndis.gov.au/applying-access-ndis/am-i-eligible</a></b></li> </ul>		
<b>Step 2</b> <ul style="list-style-type: none"> <li>Call the National Disability Insurance Agency (NDIA) on <b>1800 800 100</b> or visit <b><a href="https://www.ndis.gov.au">ndis.gov.au</a></b></li> <li>Request an <b>Access Request Form</b> (ARF). The form will be posted or emailed to you.</li> </ul>		
<b>Step 3</b> <ul style="list-style-type: none"> <li>Upon receipt, complete the NDIS <b>Access Request Form</b>.</li> <li>Try to include a letter of diagnosis from your specialist.</li> <li>Ask your doctor to complete the functional assessment section of the form.</li> <li>Other evidence, such as reports or supporting letters from specialists (e.g. occupational therapists) can be helpful, too.</li> </ul>		

Activity	Date completed	Outcome
<p><b>Step 4</b> • Return the completed NDIS access request form to the NDIA.</p> <p>After your request is assessed, you will receive an ‘access decision’ by letter, which says if you’re eligible for the NDIS.</p>		
<p><b>Step 5</b> • If you receive a letter advising that you are eligible for the NDIS, continue to Step 6</p> <ul style="list-style-type: none"> <li>• If you receive a letter advising that you are not eligible, learn more about your options by visiting <b>ndis.gov.au</b>, and find ‘<b>Receiving Your Access Decision</b>’.</li> </ul>		
<p><b>Step 6</b> • The NDIA will contact you to arrange a planning meeting to discuss your funding and support needs.</p> <p><b>Tip:</b> You can contact the NDIA and request to have this meeting face-to-face. If you haven’t received notification about your meeting, call the NDIA on <b>1800 800 110</b>.</p>		

Activity	Date completed	Outcome
<p><b>Step 7</b></p> <ul style="list-style-type: none"> <li>• Use Dementia Australia’s online NDIS planning tool, <b>yod.dementia.org.au</b>, to determine your support needs and goals.</li> </ul>		
<p><b>Step 8</b></p> <ul style="list-style-type: none"> <li>• Attend the NDIS planning meeting</li> <li>• Take your planning tool results with you to the meeting <b>yod.dementia.org.au/preparing-for-your-national-disability-insurance-scheme-ndis-planning-meeting</b>.</li> </ul> <p><b>Tip:</b> If you would like support to manage and get the most out of your NDIS plan, request ‘<b>Support Coordination</b>’.</p>		

Activity	Date completed	Outcome
<p><b>Step 9</b></p> <ul style="list-style-type: none"> <li>• After your NDIA planning meeting, your individual NDIS plan will be made and sent to you.</li> <li>• If NDIA has included Support Coordination in your plan (i.e. someone to help you manage your NDIS plan), you'll need to select a provider to deliver this service.</li> <li>• Your chosen provider will receive a <b>'Request for Service'</b> which outlines your goals and support needs in your NDIS plan.</li> <li>• From here, your Support Coordinator can help you access and implement your plan.</li> </ul>		
<p><b>Step 10</b></p> <p>Congratulations! Your individual NDIS plan has now commenced.</p>		

**This checklist is available as a separate downloadable tool for you to download and print at home to help you with each step.**



**Tip** – In your NDIS application, it's important to define how your dementia impacts your ability to participate in daily activities. For example, instead of saying 'Sometimes I experience short-term memory loss', include some specific examples, such as:

- 'Sometimes I experience short-term memory loss, which means that I can forget to take my medication.'
- 'Sometimes I forget to attend important appointments with my specialist.'

## What happens if I'm not eligible for the NDIS?

If the NDIA decides that you are not eligible for the NDIS, you can appeal this decision and request that it be reviewed by the NDIA in an internal review.

If you are unhappy with the decision of the internal review, you can then apply to the Administrative Appeals Tribunal (AAT).

Find more information about this process under the 'Receiving your Access Decision' section of the NDIS website **[ndis.gov.au](https://www.ndis.gov.au)** or by visiting the website: **[aat.gov.au](https://www.aat.gov.au)**

If you are over the age of 65, you may be eligible to receive supports and services through My Aged Care. To find out more visit: **[myagedcare.gov.au](https://www.myagedcare.gov.au)**





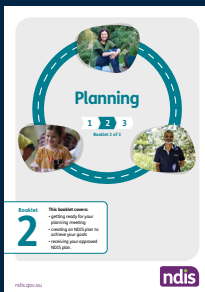


# Part two – Planning for the NDIS

- Once your NDIS access request has been approved, you will need to attend a planning meeting with a National Disability Insurance Agency (NDIA) ‘planner’ or a local area coordinator (LAC) to discuss your goals and support needs.
- Good preparation can help ensure you get the best quality NDIS plan possible.

Dementia Australia has created an online planning tool to help you prepare for your planning meeting:

**[yod.dementia.org.au/planning-tool](http://yod.dementia.org.au/planning-tool)**



Use this tool along with ‘Booklet 2 – Planning’ on the NDIS webpage:

**[ndis.gov.au/about-us/publications/booklets-and-factsheets](http://ndis.gov.au/about-us/publications/booklets-and-factsheets)**

# Tips for your planning meeting

## Meet face-to-face

- We strongly recommend meeting face-to-face. Meeting in-person will make it easier for you to communicate your goals and needs than over the phone.
- The meeting will be held at your home or at the local NDIS office.
- Meetings usually go for one to two hours.

## Prepare

- Make sure you bring any relevant documents with you, such as your completed NDIS planning tool, NDIS Planning Booklet or a list of questions you want to ask.
- You might like to print additional copies to leave with the NDIA representative if required.

## **Support**

- You can request to have a support person with you at the meeting if you wish.
- Bringing a family member, friend or carer can assist with explaining younger onset dementia to the NDIA representative.

## **Choice and control**

- Your NDIS plan is customised to your needs and choices.
- Ensure you clearly express your needs, and be honest and realistic about what you can and cannot do.

## **Be prepared for future changes**

- It's important that your plan includes support you may need as your situation changes.
- You or your support person should discuss the type(s) of dementia you have with your planner or LAC.

# Glossary

- **Coordination of Supports:**  
expert support, provided by a service provider to assist with the implementation and ongoing management of your plan. Request this at your NDIA planning meeting.
- **Formal Supports:**  
any paid carers, government funded organisations or medical specialists who help you.
- **Informal Supports:**  
any unpaid people who help you, such as family and friends.
- **Local Area Coordinator (LAC):**  
local organisations working in partnership with the NDIA to help participants, their families and carers access the NDIS.

- **myplace Participant Portal:**  
where you access your NDIS plan online. The portal also shows how much funding you have available for each service type in your plan. You can access the portal on the NDIS website **ndis.gov.au**, once your plan has been approved.
- **National Disability Insurance Agency (NDIA):**  
the NDIA delivers the NDIS.
- **National Disability Insurance Scheme (NDIS):**  
the NDIS is a national government-funded program which provides reasonable and necessary support to people under the age of 65 with a permanent and significant disability.
- **Participant:**  
a person who is eligible for the NDIS.
- **Plan:**  
a written agreement worked out with the participant, stating their goals and needs, and the reasonable and necessary supports the NDIS will fund.
- **Provider:**  
an organisation or individual that provides a service through an NDIS package.



## About Dementia Australia

Dementia Australia is the source of trusted information, education and services for the estimated half a million Australians living with dementia, and the almost 1.6 million people involved in their care.

We advocate for positive change and support vital research. We are here to support people impacted by dementia, and to enable them to live as well as possible.

No matter how you are impacted by dementia, we are here for you.

Founded by carers more than 35 years ago, today we are the national peak body for people living with dementia, their families and carers. 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. We amplify the voices of people impacted by dementia through advocating and sharing stories to help inform and inspire others.

# National Dementia Helpline

## 1800 100 500



For language assistance  
call **131 450**

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Find us online  
**dementia.org.au**

