Younger onset dementia and the NDIS

A pathway to support
This booklet was prepared by Dementia Australia for people living with younger onset dementia, their carers, families and friends.

Information included in this booklet was accessed from the following sources:

- National Disability Insurance Scheme – ndis.gov.au
- Personal experiences of people living with younger onset dementia and carers.

NDIS stands for National Disability Insurance Scheme.
The NDIS is provided through the National Disability Insurance Agency (NDIA)

Dementia Australia respectfully acknowledges the Traditional Owners of the land throughout Australia and their continuing connection to country. We pay respect to Elders both past and present and extend that respect to all Aboriginal and Torres Strait Islander people who have made a contribution to our organisation.

Disclaimer: This booklet is for information purposes. The tips and suggestions provided in this guide are general in nature and do not take into account your specific circumstances. We recommend that you seek professional advice in relation to any specific concerns or issues that you may have.

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Is this booklet for you?

This booklet has been developed for people living with younger onset dementia and their friends and families who are seeking information on the National Disability Insurance Scheme (NDIS). Our aim is to assist you to better understand the NDIS and how to access the services and supports needed to achieve your goals.

What is younger onset dementia?

The term ‘younger onset dementia’ is used to describe any form of dementia diagnosed in people under the age of 65. Dementia describes a collection of symptoms that are caused by disorders affecting the brain. It is not one specific disease. There are many types of dementia. Each type has its own symptoms and signs, and is caused by a specific type of change in the brain. The most common causes of younger onset dementia are Alzheimer’s disease, stroke and frontotemporal dementia. Dementia affects thinking, behaviour and the ability to perform everyday tasks. Over time, brain function is affected and begins to interfere with the person’s regular home, social and working life.

Based on recent research, it is estimated that more than 25,938 people in Australia are currently living with younger onset dementia.

More information about dementia, including younger onset dementia can be found on the Dementia Australia website dementia.org.au
The National Disability Insurance Scheme (NDIS) is a Commonwealth Government program providing support to people under the age of 65 with a permanent and significant disability; younger onset dementia is included in this program. This means people living with younger onset dementia are able to apply through the NDIS for reasonable and necessary funding and support to achieve their goals, maintain their wellbeing and continue to participate in community life. The NDIS is delivered by the National Disability Insurance Agency (NDIA) and is being progressively introduced across Australia. It is anticipated the scheme will be fully operational by 2019.

More details of the program in your state or territory can be found on the NDIS website ndis.gov.au

The amount of support received from the NDIS is individually determined based on your specific needs, not on your income and assets. This means that the NDIS is not means tested, and all Australians living with younger onset dementia are eligible to apply for support through the NDIS. The eligibility criteria for the NDIS will take into consideration your age, residency status and the impact of your dementia on your wellbeing. If you are eligible for the NDIS, an individual support plan will include funding to purchase services, aids and equipment that you have been assessed as needing. Your first plan will generally be in place for 12 months before it is reviewed to ensure it continues to meet your needs and goals as they change over time. Future plans may vary in length depending on your individual circumstances.
“It has changed my mum’s life. She has more time to look after herself, she is happier and exercises ... it is a load off me as well”

Nina – daughter of a person living with younger onset dementia
The NDIS has been designed to support people living with a disability, including younger onset dementia, to:
access mainstream services and supports; access community services and supports; maintain informal support arrangements; and receive reasonable and necessary funded supports. All support plans are individually tailored to meet your specific needs but may include items such as:

- Assistance in the home including gardening, cleaning, home maintenance, specialised equipment, assistive technologies and building modifications.
- Support with daily activities such as showering, dressing, preparing meals and medication management.
- Support to maintain social relationships and to participate in activities and interest groups of your choice.
- Assistance to maintain physical health and wellbeing including access to exercise activities and other therapies such as speech pathology, physiotherapy, occupational therapy, and dietary advice.
- Expert support to assist with the implementation and ongoing management of your chosen services and activities (coordination of supports).
- Individual employment support to assist you to find or maintain paid or voluntary occupational activities.
- Assistance with the development of a behavioural support plan including training for carers and others in behavioural management strategies.
- Support to access a community activity or holiday.
- Choice of self-management, or support from a Plan Manager, or the NDIA, with the financial management of your plan.
Younger Onset Dementia Key Workers

You are not alone. Dementia Australia Younger Onset Dementia Key Workers are available to assist people living with younger onset dementia and their families and friends to access the support and information they need. After being referred to Dementia Australia, a Key Worker will be allocated to provide you with individualised support to assist you to better understand younger onset dementia and provide you with up-to-date information, resources and assistance to access the NDIS.

When a Key Worker assists you to access the NDIS, they bring with them a wealth of knowledge and experience about dementia and how younger onset dementia fits within the disability framework. This experience supports you to receive the best possible individual plan to help you achieve your specific goals and needs. Dementia Australia is a registered NDIA service provider, which means we are also able to provide assistance with the coordination of your supports and other services that may be included in your plan. More information on Coordination of Supports can be found on page 13.

To request support from a Younger Onset Dementia Key Worker please call the Dementia Australia National Dementia Helpline on 1800 100 500.

“A Key Worker is invaluable. I could never have got so much help without her”

Ashton – living with younger onset dementia
To access the range of supports available through the NDIS, you will need to register with the NDIA, who will assess your eligibility for support based on the information you provide. If you are eligible, a planning meeting will be arranged where you will be able to discuss your goals and support needs with an NDIS authorised planner. This will assist with the development of your individual support plan for the first 12 months. The planner will ask you about your current situation and how you undertake everyday activities. It is always preferable to request a face-to-face meeting with your planner as this makes communication easier and reduces the potential for misunderstandings. Preparation for these planning meetings is highly recommended to ensure you receive the supports that best meet your individual needs and situation.

Following approval of your individual support plan, funds will be allocated to enable you to implement your plan. The NDIA can support you to do this, or if your plan includes a Coordination of Supports, your Key Worker in the Support Coordination role will be able to assist you to choose your providers and start your plan. Remember, you get to choose your own providers and how this support is delivered.

The checklist on the following pages may be a useful guide when you start to access the NDIS.
Following the steps in this checklist will assist you to access support through the NDIS and monitor your progress along the way.

## Access checklist

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<td><strong>STEP 1</strong> If you would like support to access the NDIS, a good first step is to <strong>request the assistance of an Dementia Australia Younger Onset Dementia Key Worker</strong> by phoning the National Dementia Helpline on <strong>1800 100 500</strong>. A Key Worker will be allocated who will assist you to access services from the NDIS.</td>
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<td><strong>STEP 2</strong> <strong>Contact the NDIA and request an NDIS access request form</strong>. This can be done by phoning <strong>1800 800 110</strong> and having the form posted or emailed to you. More information about the NDIS can be found at <strong>ndis.gov.au</strong></td>
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<td><strong>STEP 3</strong> <strong>Once you have received the NDIS access request form, complete the form</strong> yourself or contact your Key Worker for assistance. It is recommended that you include a letter of diagnosis from your specialist and have your doctor complete the functional assessment section of this form to support your application.</td>
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<td><strong>STEP 4</strong> <strong>Return the completed NDIS access request form to the NDIA</strong>. The form will be processed and you will be advised by letter if you are eligible for the NDIS.</td>
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<td><strong>STEP 5</strong> <strong>Letter received from the NDIA advising you of your eligibility for the NDIS.</strong></td>
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<td><strong>STEP 6</strong></td>
<td>If you have requested Key Worker support, arrange a discussion with your Key Worker to <strong>determine your needs, goals and the supporting information required</strong>. This will help to prepare for your planning meeting with the NDIA. The NDIA will write to you and advise you of the date of your planning meeting.</td>
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<td><strong>STEP 7</strong></td>
<td><strong>Once you have received a letter or telephone call advising you of the date for your NDIS planning meeting, start final preparations for the meeting.</strong> If you have a Key Worker, it is important you advise them of the date of this meeting so they can support you through the process. Don’t forget to request a face to face meeting.</td>
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| **STEP 8** | **Attend the NDIS planning meeting to discuss your goals and the support you require to achieve these goals over the next 12 months.** Where possible your Key Worker will support you at this meeting.  
If you are receiving supports from Dementia Australia and would like these to continue, it is important you request this at your planning meeting. You could also request ‘Coordination of Supports’ if you would like support from your Key Worker to implement and coordinate your plan. |
| **STEP 9** | Following this meeting **your individual NDIS plan is developed and mailed out to you**. If a Support Coordinator has been included in your plan, a copy will also be sent to them so they can assist you to implement your plan. |
| **STEP 10** | **Work with your Key Worker (referred to as a Support Coordinator in the NDIS) or the NDIA to decide which services and supports you would like to access and implement these services.** Your individual NDIS plan has now commenced. |
“Coping with dementia is difficult enough; by taking away those worries like cleaning and gardening, I am better able to cope with dementia”

George – living with younger onset dementia
In some cases, a Support Coordinator may be funded as part of your individual plan, depending on whether it is considered a reasonable and necessary support. A Support Coordinator will help you to maximise the value for money you receive from your plan and will also assist you to coordinate multiple supports and services. Dementia Australia is registered with the NDIS to provide Support Coordination and a range of other NDIS services.

**Why choose Dementia Australia as your Support Coordinator?**

Our years of dementia experience and expertise, and our established networks with services supporting people living with younger onset dementia, make us the perfect choice to be your Support Coordinator.

If appointed as your Support Coordinator, your Dementia Australia Key Worker will work with you to understand your needs and assist you to implement your plan and achieve your goals. The choice and control is yours. We can:

- assess all types of support options and assist you to choose your preferred providers;
- negotiate on your behalf for services to be provided, including prices, service agreements and bookings;
- work with your Plan Manager and other providers to ensure that your plan delivers maximum value;
- assist you to resolve problems or issues that may arise;
- support you to review goals and consider new ones;
- help you to prepare for reviews of your plan.
Tina was diagnosed with younger onset dementia two years ago and lives with her husband Jim. Following her diagnosis, Tina requested support from a Younger Onset Dementia Key Worker, who provided both Tina and Jim with information and support to continue to live well. When the NDIS commenced in Tina’s area, her Key Worker supported her to understand the process and assisted her to access the scheme. Both Tina and Jim described their Key Worker as “invaluable; they made the whole process so much easier for us to understand. They provided just the right amount of information and support and assisted us all the way through the process”.

Through accessing the NDIS, Tina has been able to continue going to her weekly social group and also has other regular activities scheduled to maintain connections with her local community. Coordination of Supports was allocated and delivered by her Key Worker, and domestic assistance and gardening services were introduced. These services have enabled Tina to continue to live well in her own home.

As a result of Tina’s supports, Jim now has more time to pursue his interests including painting and doing voluntary activities.

“When my Key Worker told me what might be possible with the NDIS, I was sceptical, but I have to admit I was wrong. My quality of life has improved and I am very happy with the support I am receiving”
Hints and tips

**Begin paperwork as soon as possible**

Sometimes, time delays can occur between receiving documents, attending appointments and accessing services. Delays may vary from weeks to months so it is important to start the paperwork as soon as possible. Follow up with the NDIA about the progress of your application if you are concerned about a time delay.

**Arrange a face-to-face planning meeting**

It is often easier to discuss your goals and service needs at a face-to-face meeting than over the phone. When contacted by the NDIA to arrange your planning meeting, please request a face-to-face meeting so you are better able to communicate your needs and goals. Your Key Worker will be able to assist you to prepare for this meeting and offer support throughout the process.

**Be aware that your care needs change with time**

Before attending your planning meeting it is a good idea to consider the future and how your needs might change over the next 12 months. Discussing your future needs with your Key Worker before your planning meeting will help you prepare for your meeting and assist your NDIS planner to better understand the impacts of younger onset dementia on your life.
Prepare for your planning meeting

Thorough preparation before your planning meeting with the NDIA can make a big difference to the quality of the plan you receive. Before attending the meeting, take time to think about what types of support you need and why, and prepare any questions. You may find it helpful to think about what is important to you in everyday life. Also think about what type of support will assist you to maintain who you are and continue to do what is important to you. Your Key Worker will be able to assist you to prepare for your meeting.

Learn from others’ experiences

Many people living with younger onset dementia have already engaged with the NDIA. If you would like to benefit from or learn more about their experiences, have a chat to your Key Worker who may be able to connect you with others. You can also visit the Younger Onset Dementia Online Forum, a forum to share questions, concerns and your story with others living with younger onset dementia – talkdementia.org.au
Frequently asked questions

Why do people with younger onset dementia need to have a NDIS plan?

Many people living with younger onset dementia are not getting enough services and supports. Applying for and receiving an Individual NDIS plan will assist you to access the supports and services you need to achieve your goals and continue to live well with younger onset dementia.

How are services paid for?

Your plan will include an allocation of funds to support the purchase of services and supports for the next 12 months. When these services are provided, they will be charged back to your plan. If you have an appointed Plan Manager they will look after the finances for you, or you may choose to look after the finances yourself or have the NDIA manage them for you. If you have a Plan Manager or are managing the finances yourself, you will also be able to purchase supports from providers that have not registered with the NDIA. Your Key Worker will be able to assist you to decide if self-management will work for you.

What if I choose to enter residential care?

If you decide to access full time residential care you will require a specialist assessment conducted by the Aged Care Assessment Team (ACAT). An ACAT assessment is arranged through My Aged Care by calling 1800 200 422. You may be asked to contribute towards the costs of residential care which are not covered by the scheme. However, you will remain eligible for some NDIS supports whilst living in residential care. The NDIA or your Key Worker will be able to provide you with more information if you choose to access residential care.
To watch a short video of people with younger onset dementia talking about dementia and the NDIS, visit dementia.org.au/about-dementia/resources/videos

National Disability Insurance Scheme
1800 800 110
ndis.gov.au