



# **NATIONAL DISABILITY INSURANCE SCHEME (NDIS)**

**TOOLKIT FOR PEOPLE LIVING WITH  
YOUNGER ONSET DEMENTIA  
AND THEIR CARERS**

**UNDERSTAND ALZHEIMER'S  
EDUCATE AUSTRALIA**  
FIGHTDEMENTIA.ORG.AU

## ACKNOWLEDGEMENTS

Alzheimer's Australia NSW thanks the NSW Department of Family and Community Services for funding this resource.



The information provided is correct as at June 2017.

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## NDIS GLOSSARY

**Coordination of Supports:** a provider to help you implement your NDIS plan and access services.

**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 [www.ndis.gov.au](http://www.ndis.gov.au)

**National Disability Insurance Agency (NDIA):** the NDIA delivers the NDIS.

**National Disability Insurance Scheme (NDIS):** the NDIS is a national program which provides 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 for them.

**Provider:** an organisation or individual that provides a service through an NDIS package.

## ABOUT ALZHEIMER'S AUSTRALIA

Alzheimer's Australia represents people with dementia and their carers.

Alzheimer's Australia provides support services, education, information and advocacy, as well as the National Dementia Helpline and the Younger Onset Dementia Key Worker Program.

The Alzheimer's Australia website is [www.fightdementia.org.au](http://www.fightdementia.org.au)

For information and assistance you can call the **National Dementia Helpline** on **1800 100 500** or email [helpline.nat@alzheimers.org.au](mailto:helpline.nat@alzheimers.org.au)

## WHAT IS THE NATIONAL DISABILITY INSURANCE SCHEME (NDIS)?

The National Disability Insurance Scheme (NDIS) is a national program that provides support to people under the age of 65 with a permanent and significant disability through individualised funding that is allocated directly to the participant.

The NDIS is delivered by the National Disability Insurance Agency (NDIA). It is expected that the NDIS will be fully operational by July 2018. **More details about the NDIS can be found on the NDIS website [www.ndis.gov.au](http://www.ndis.gov.au). You can also call the NDIA on 1800 800 110 from 8am to 11pm, Monday to Friday.**

## WHO IS ELIGIBLE FOR THE NDIS?

To access the NDIS you must meet eligibility requirements.

You need to:

- Have a permanent disability, such as younger onset dementia, that significantly affects your ability to take part in everyday activities
- Be aged under 65 years when you register for the NDIS
- Live in Australia
- Be an Australian citizen, or hold a permanent visa or a Protected Special Category visa.

## WHAT IS THE PURPOSE OF THIS TOOLKIT?

This toolkit is for people with younger onset dementia and their carer/s or support person. It provides information, advice and guidance to help you apply for the NDIS and prepare to develop an NDIS plan.



## HOW WILL AN NDIS PLAN BENEFIT ME?

If you are eligible, an NDIS plan will be developed with you. Based on this plan, you will receive funding on an annual basis to purchase the services, aids and equipment you need. As your circumstances change, you can apply to have your plan reviewed and adjusted accordingly.

The NDIS is not means tested. The amount of support you receive from the NDIS is based on your specific needs, not on your income and assets.

### CASE STUDY

Carole has younger onset dementia and mobility issues. Her husband has been her primary carer for several years. He was constantly exhausted and had severe back pain from lifting Carole and assisting her around the house.

The NDIS provides Carole with support from home care workers who help her maintain her independence around the home and give her husband a break. Their relationship has improved as a result.

Each week Carole attends a day centre. She enjoys the social interactions this provides. Carole also does hydrotherapy which has helped her become more mobile.

Carole says “the NDIS has been an amazing support and continues to empower me to improve my own quality of life and support those I love”

## NDIS REGISTRATION AND APPLICATION

The first thing you need to do is register your interest for the NDIS by calling the NDIA on **1800 800 110**.

The NDIA will send out an access request form to determine your eligibility for the NDIS. You need to complete this form (and your GP needs to complete section F) then return it to the NDIA with:

- Medical evidence of your condition e.g. a letter from your specialist confirming your diagnosis of younger onset dementia
- A letter of support from an advocate such as a Younger Onset Dementia Key Worker (not required but recommended)

The NDIA may take a few weeks to respond to your application and confirm your eligibility status for an NDIS plan.

If you are eligible, a Local Area Coordinator (LAC) will contact you to arrange a meeting with an NDIA representative to develop your NDIS plan.

### WHAT 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 not happy with the decision of the internal review, you can then apply to the Administrative Appeals Tribunal (AAT). More information about the NDIS appeals process is available at: <https://www.ndis.gov.au/about/contact-us/feedback-complaints/appeals-tribunal>

## PREPARING TO DEVELOP YOUR NDIS PLAN

It is important to spend some time preparing for your meeting with the NDIA representative to develop your NDIS plan. A key worker or an advocate can help you during this process. You might like to meet with them face-to-face or over the phone.

The amount of NDIS funding you receive depends on how much support you need. As dementia is a progressive neurodegenerative condition, it is important to plan for support to cover your future needs and changing circumstances.

Also consider the capacity, ability and health of your carer/s. For example, if they also have a medical condition they may not be able to provide as much help in the future and you will need increased services or overnight supports.

As the symptoms of younger onset dementia can fluctuate, it is best to develop your NDIS plan from the perspective of a 'bad day' or when your dementia symptoms are at their worst – think about what help you need during these times.

The information on the following pages will help you prepare for your planning meeting.

### DAILY AND WEEKLY SCHEDULE

The NDIA will want a day-to-day account of how much help and support you need. Think about this based on a typical day and include things like meal preparation, dressing, personal care, assistance with activities, transport, and help you require during the evenings and overnight.

What is your current weekly or daily schedule? What does your usual week look like? Doing an assessment of your everyday life can also help you identify goals you want to achieve with the support of the NDIS.

**Example of a daily schedules for a week for a person with younger onset dementia (noting what support they receive from formal supports e.g. in-home services, community access, personal care, domestic assistance, and informal supports e.g. spouse)**

Time of day	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
<b>Morning 1am – 12pm (NOON)</b>	About 7:30 am get up and have breakfast and then shower. Supported  About 10am, grocery shopping. Supported.  Carer prepares lunch for both of us. Supported	About 7:30 am get up and have breakfast and then shower. Supported  Domestic assistance x 2 hours  Carer prepares lunch for both of us. Supported	About 7:30 am get up and have breakfast and then shower. Supported.  9:30am Respite centre, X 6 hours social support  I join in on the activities for the day.	About 7:30 am get up and have breakfast and then shower. Supported.  About 10am, go with Carer to do grocery shopping. Supported.  Carer prepares lunch for both of us. Supported	About 7:30 am get up and have breakfast and then shower. Supported.  Domestic assistance x 2 hours  Carer prepares lunch for both of us. Supported.	About 7:30 am get up and have breakfast and then shower. Supported.  About 10am, grocery shopping Supported.  Carer prepares lunch for both of us. Supported	About 7:30 am get up and have breakfast and then shower. Supported  Carer prepares lunch for both of us. Supported  On occasions, we go out for lunch on Sundays. Supported
<b>Afternoon 12pm (NOON) – 6pm</b>	Have lunch at 12pm. Supported.  Social support x 2 hours: Swim/walk  Carer prepares dinner about 5:30pm. Supported.	Have lunch at 12pm. Supported.  Watching the midday TV shows.  Social support x 2 hours: Swim/walk  Carer prepares dinner about 5:30pm. Supported.	At respite centre until about 3pm. Carer picks me up and takes me home. Supported.  Carer prepares dinner about 5:30pm. Supported.	Have lunch at 12pm Supported.  Social support x 2 hours: Swim/walk  Carer prepares dinner about 5:30pm. Supported.	Have lunch at 12pm watching the midday TV shows.  Social support x 2 hours: Swim/walk  Carer prepares dinner about 5:30pm. Supported.	Have lunch at 12pm Supported.  Carer prepares dinner about 5:30pm. Supported.	Have lunch at 12pm watching the midday TV shows. Supported.  Carer prepares dinner about 5:30pm Supported.
<b>Night 6pm – 12am (MIDNIGHT)</b>	Have dinner Supported.  Watch TV until 8:40pm.  Get ready for bed. In bed about 9pm	Have dinner Supported.  Watch TV until 8:40pm.  Get ready for bed. In bed about 9pm	Have dinner Supported.  Watch TV until 8:40pm.  Get ready for bed. In bed about 9pm	Have dinner Supported.  Watch TV until 8:40pm.  Get ready for bed. In bed about 9pm	Have dinner Supported.  Watch TV until 8:40pm.  Get ready for bed. In bed about 9pm	Have dinner Supported.  Watch TV until 8:40pm.  Get ready for bed. In bed about 9pm	Go to 6pm local church service.  Have dinner Supported. Watch TV until 8:40pm.  Get ready for bed. In bed about 9pm

**A blank copy of this daily schedule chart is in the appendix of this toolkit. It is helpful to complete this as you prepare for your NDIS meeting.**

## PARTICIPANT STATEMENT

A participant statement tells the NDIA what your current circumstances are and lets them know how you want the NDIS to help you.

Here is an **example of a NDIS participant statement** for a person living with younger onset dementia.

### **Where I live and the people I live with** (your current living arrangements)

I live with my wife and don't use any services. My social network is small.

My house is a long way from the local shops and services. I can no longer drive and can't take public transport without help. I rely on my wife to drive me to appointments.

Due to my dementia I struggle with basic household and personal tasks. My wife does all the shopping, takes me to appointments, etc.

I feel very isolated and alone. I am alone four days a week from 7am to 7pm while my wife is at work and also alone on one night of the week as my wife has elderly parents who she visits.

We live in rented accommodation; the owners are trying to sell which means we will probably need to move.

People in my life who support me (the important people in your life and how they support you – this might include family and friends, your doctor, your carer or others.)

**Informal support:** My wife is my primary carer. She tries to help me on a daily basis but works full time. She is getting exhausted and needs help. I want to spend quality time with her but to do this I need to have more support to assist me in my daily life and enable me to access the community.

We have no immediate support if an emergency situation were to occur at home. I have a good relationship with my GP. We have two children that lead full busy lives and see us infrequently. They are great emotional supports but can't help out with the practicalities.

**Formal support:** Apart from the support from Alzheimer's Australia and the Younger Onset Dementia Key Worker program I have no formal support.

**A blank copy of the Participant Statement for you to complete in preparation for your NDIS meeting is in the appendix of this toolkit.**

## CARER STATEMENT

In addition to the participant statement, we recommend that carers of people with younger onset dementia also provide a carer statement. This is a personal statement (1-2 pages) written from a carer's perspective to let the NDIA know how the caring role impacts on their life. Here are some ideas about the type of information to could include in a carer statement:

- General information about the person you care for and your life together
- How you care for and assist a person with younger onset dementia
- How you feel about the caring role and the impact it has on yourself and your relationship
- How your life has changed since the person you care for developed younger onset dementia
- What you and the person you care for want from the NDIS

**A Carer Statement template is provided in the appendix of this toolkit.**

## NDIS GOALS

It is important to tell the NDIA about your goal/s. These will be listed in your NDIS plan to let the NDIA know what is important to you and what support you need. It is useful to prioritise your two main goals prior to your NDIS meeting.

**When thinking about your goals, ask yourself questions such as:**

- What are the things that are most important to me?
- What are the things I would most like to change?
- What would I like to do with less help from others?
- Are there new things I would like to try?

**You might have goals in different areas of your life including:**

- Daily life
- Living arrangements
- Relationships
- Health and wellbeing
- Learning
- Work
- Social and community activities
- Choice and control

**There is an extended checklist in the appendix to help you think about your circumstances and identify goals you want to achieve with the support of the NDIS.**

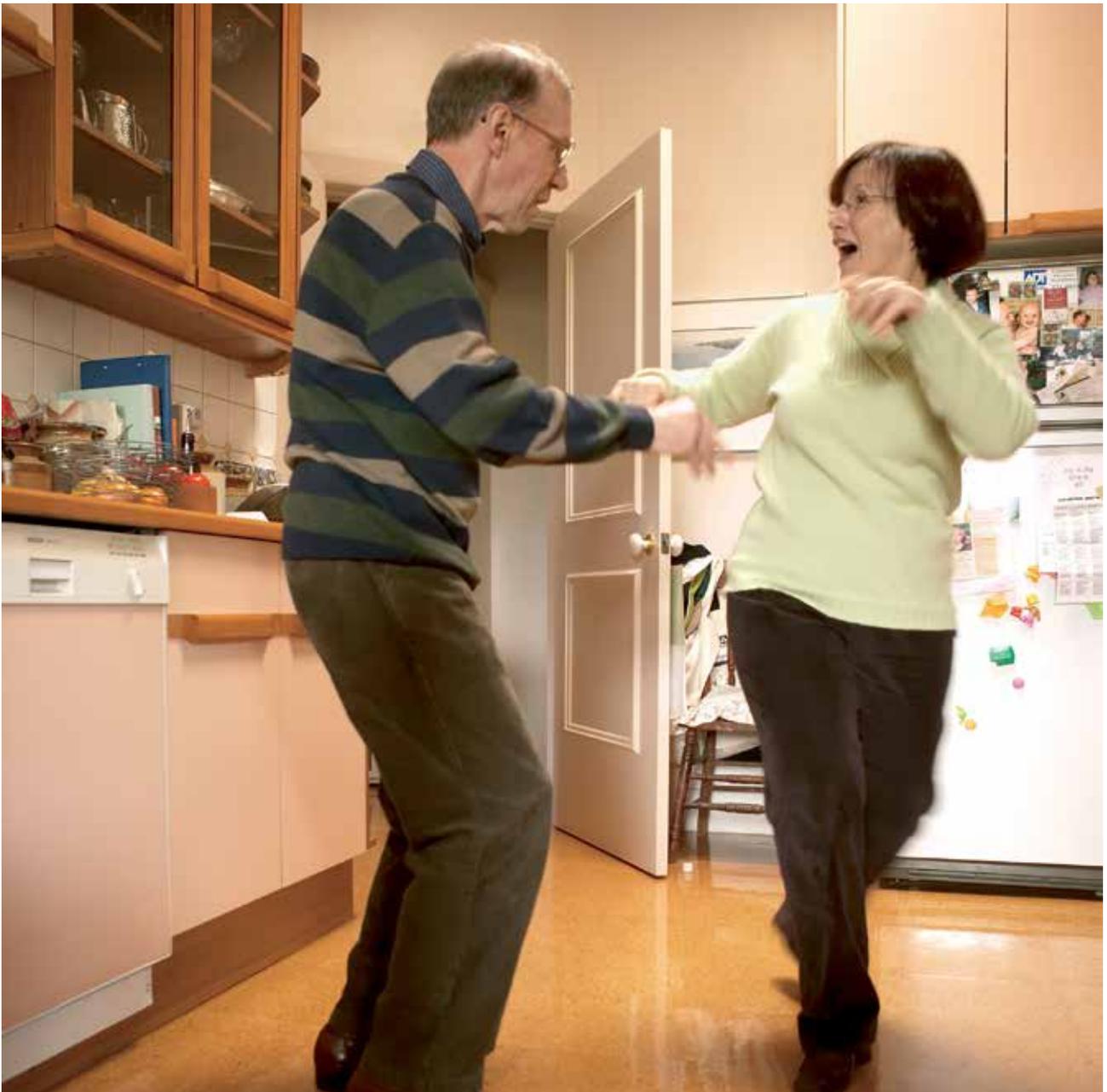
**Developing Goals – Examples of common goals that people with younger onset dementia often have and how the NDIS can support them, are in the table below. It’s best to give top priority to your 2 main goals.**

Goal	What I need to achieve this goal
<p><b>1. I want to have greater access to community and social activities, to build and maintain friendships in the community.</b></p>	<p>Current feelings of isolation and loneliness would be alleviated by 1-1 social support to build my confidence in social situations</p> <p>Funding for a day centre for Monday and Thursday from 10am – 4pm</p> <p>Transport</p> <p>Funding x 4 a week: For example every week I would attend an appointment, x 3 social activities</p>
<p><b>2. I want to have my everyday needs met and feel safe and secure in my own home.</b></p>	<p>In-home support, assistance with daily self-care tasks. I can no longer cook or shop without assistance.</p> <p>Assistance with household tasks. I need help to clean my house, e.g. throw out of date items away.</p> <p>Ideally</p> <p>4 x hrs a week of shopping assistance with a pre-planned shopping list</p> <p>2 x hrs a day, 10 x hrs a week of cooking assistance, I can no longer make a cup of tea without assistance. I also need 1-1 assistance with taking medication during meal times.</p> <p>2 x hrs a week for household supported cleaning</p>
<p><b>3. I want to regularly exercise to help maintain a healthy brain and body</b></p>	<p>NDIS to provide me with support for informal supports (social support) which will allow 1 -1 support whilst exercising x 8 hours a week</p> <p>Carers to accompany me to classes/ on walks x 3 week</p> <p>Physiotherapist to have an hourly fortnightly session to maintain my current strength and mobility and also conduct cognitive stimulating activities.</p>
<p><b>4. I want support to maintain my independence for as long as possible as well as minimise my carer’s fatigue.</b></p>	<p>Occupational Therapist support for 12 hrs- Assessment for home modification, assistive technology suggestion/purchase/instruction.</p> <p>Day centre attendance</p>
<p><b>5. I want help to manage services as I no longer have capacity.</b></p>	<p>Funding for coordinator of supports from a provider that I choose to assist me to arrange and manage my support services for 3 hours a week.</p>

**A blank copy of this Developing Goals chart for you to complete in preparation for your NDIS meeting is provided in the appendix of this toolkit.**

**Note – the NDIS will fund the cost of products you may need to achieve your goals and to support you to live well with younger onset dementia. This includes:**

- Contenance products
- Meal delivery services (the cost of ingredients is not covered but generally 75% of overall cost is covered)
- Assistive technologies such as Kisa (dementia-friendly) mobile phones, speak to text programs (e.g. Dragon talk), audio books, kitchen safety equipment (e.g. water temperature regulators, automatic switches for stove tops), apps for iPads. You can purchase these with NDIS funds and you own them.
- Occupational therapy (OT) assessments for home modifications and the modifications you require for your home (e.g. grab rails in the bathroom, coloured toilet seats etc.).



## INFORMATION ABOUT YOUNGER ONSET DEMENTIA FOR THE NDIA

An information sheet about younger onset dementia is in the appendix of this toolkit.

This information sheet can be given to the NDIA representative during your planning meeting. This will help them understand the impact of younger onset dementia.

You can add personal information to this sheet - outline the symptoms you experience, how younger onset dementia has changed your life and how this impacts on your day-to-day life and your carer and/or family.

You may also wish to give the NDIS representative an information sheet about your specific type of dementia such as Alzheimer's disease, frontotemporal dementia, etc. These information sheets are available from the **Alzheimer's Australia website [www.fightdementia.org.au](http://www.fightdementia.org.au)** or by calling the **National Dementia Helpline on 1800 100 500**.

## WHAT TYPE OF PLAN MANAGEMENT DO I NEED?

Your NDIS plan will include funds to pay for your services and other supports for the next 12 months. It is helpful to discuss the options for how your plan can be managed with your key worker, advocate or other support person before your planning meeting to determine the most suitable option for you.

### There are four plan management options:

1. Self-managed: you manage all payments and can choose any service providers. This enables more flexibility in your choice of services however you initially pay for your services upfront and then claim for reimbursement through the NDIS.
2. Plan management: a third party pays the providers from your NDIS budget and you can choose any providers. Administration costs associated with this form of management are built into the plan.
3. NDIA managed: the NDIA pays the providers directly but you can only choose to have services provided from NDIS registered providers. The NDIA has information about how to find registered services at: <https://www.ndis.gov.au/document/finding-and-engaging-providers/find-registered-service-providers.html>
4. Combination approach: the above ways can be combined for different parts of your plan.

Further information about NDIS plan management is available on the NDIS website at: <https://www.ndis.gov.au/participants/understanding-your-plan-and-supports.html>

Regardless of which plan management option you choose, you remain in control of which service providers you select, as well as when and how help is provided.

## CASE STUDY

Nancy moved from Scotland to Australia 20 years ago with her husband. Nancy was a teacher and had always been very active and social.

Nancy was diagnosed with Multiple Sclerosis and Alzheimer's disease in her 50s. She had to retire from teaching and stop driving. Then her marriage broke down. With no family in Australia and a lack of social support, Nancy's dementia progressed.

The NDIS has helped Nancy immensely. She receives daily home care, attends a day centre and has therapeutic supports. Nancy is currently able to live on her own and has formed strong connections with her carers and others at the day centre.

The NDIA staff collaborate with Nancy and her advocates to enable her to live in the community and enjoy her life.



## MEETING TO DEVELOP YOUR NDIS PLAN

This meeting is your opportunity to let the NDIA know what support you need from the NDIS. An NDIA representative (usually a LAC or an NDIA planner) will meet with you to discuss your goals and develop a plan of support for you.

It is useful to request a face-to-face meeting with the NDIA representative rather than communicate with them over the phone. Meeting face-to-face will make it easier for you to communicate your goals and you can have a support person with you at the meeting if you wish. The meeting will be held at your home or at the local NDIS office. Meetings usually go for 1-2 hours.

Make sure you have the documents you developed during your preparations with you and have copies to leave with the NDIA representative if required.

### BEFORE AND DURING YOUR MEETING, REMEMBER:

**You have choice and control:** The NDIS is built on the principle of client choice and control.

**Speak out:** Be vocal about your needs. Be honest and realistic about what you can and cannot do.

**Be specific:** During the meeting there will be a number of questionnaires to answer. These questionnaires are designed to see what level of support you need. Make sure you request that the NDIA representative includes your individual needs in these reports.

**Be prepared for future changes:** As dementia is a neurodegenerative disease, it is important your plan includes supports that you may need as your situation changes. Discussing the type of dementia you have with the NDIA representative so they understand your condition and symptoms will help with this. A Younger Onset Dementia Key Worker or advocate can assist with explaining younger onset dementia to the NDIA representative, if you do not feel comfortable or equipped to do so.

**You can request support:** We strongly recommend that you request Coordination of Supports in your plan. This is an organisation funded within your NDIS plan to help you understand your plan and help you find and connect with appropriate services. Support coordination enables NDIS participants to maximise the value for money they receive from their plan while enhancing their ability to coordinate multiple supports and services. For people with younger onset dementia, a coordinator of supports can provide important assistance with planning ahead for future needs and services, particularly when insight is limited and capacity may fluctuate. You can request that an Alzheimer's Australia Younger Onset Dementia Key Worker be your Coordinator of Supports.

## WHAT HAPPENS NEXT?

After the meeting, an NDIS planner will use all the information collected to prepare your NDIS plan. Once you receive your plan, it is important to check it to make sure you are happy with what has been included. If coordination of supports has been included, the nominated organisation will be able to help you implement your plan. If coordination of supports has not been included, we suggest you contact your LAC and request their assistance to implement your plan.

The NDIA website has information to help you to get your plan started. This is available at:

<https://www.ndis.gov.au/participants/startingmyplan>

With the assistance of your coordinator of supports or LAC, you will need to choose service providers and sign service agreements with them. The NSW Government toolkit Guide to Choosing a Service Provider is helpful. This is available at:

[https://www.adhc.nsw.gov.au/\\_\\_data/assets/file/0003/414579/Guide-to-Choosing-a-Service-Provider-FINAL.pdf](https://www.adhc.nsw.gov.au/__data/assets/file/0003/414579/Guide-to-Choosing-a-Service-Provider-FINAL.pdf)

## PLAN REVIEWS

The NDIA will review your plan every 12 months to make sure that it is still meeting your needs. A review can be requested earlier if:

- You believe your plan is not meeting your needs
- Your circumstances change (e.g. your symptoms progress, your relationship changes, you can no longer drive etc.)
- You wish to change your plan management arrangements
- You require an increase, decrease, or change in supports.

Your coordinator of supports, LAC, Younger Onset Dementia Key Worker or other advocate can assist you in this review process.

### CASE STUDY

Andy had an NDIS package to support him to live at home with his wife. However, as his dementia progressed it became difficult for him at home and he needed to move into an aged care home where dementia-specific care could be provided.

Following a plan review, Andy continues to receive support through the NDIS while in living in residential aged care. Andy's new NDIS goals are to see his family and friends outside of the aged care home and to keep walking as much as possible.

His plan now includes meeting friends for a drink at the local club. A support worker goes along so Andy and his friends can enjoy each other's company without having to worry about personal care tasks. The plan also provides a support worker to help Andy and his wife attend medical appointments and visit family.

There is minimal one-on-one physiotherapy provided in the aged care home so the NDIS plan provides for extra physio sessions each week and the physiotherapist has also taught the aged care staff and Andy's wife how to help him with his exercises.

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## I. NDIS PLANNING CHECKLIST

This checklist will help you think about the different types of information you need to prepare for your meeting with an NDIA representative to develop your plan. You can write notes in the spaces provided.

### Living arrangements

- Who do you live with?
- Would you prefer to change your current living arrangement?
- Are you responsible for maintaining your accommodation?

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### Who are the people that support you?

- Your partner/spouse
- Family members
- Doctor/medical professional
- Support group
- Friends
- Respite services
- YOD Key Worker Program
- Volunteer
- No informal supports
- Others

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### Who provides most of your care and support (primary carer)?

- Does your carer live with you?
- Does your carer also support someone else?
- Is your carer currently employed?

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# APPENDICES

## What do you need help with at home?

- Personal care
- To move around home
- Meal preparation
- Domestic assistance
- Planning and problem solving
- My health
- Communicating with others

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## What is important for you to maintain?

- Your living arrangement
- Family, relationships and activities
- Access to the community
- Employment
- Volunteering
- Health and Wellbeing
- Safety

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## What are the symptoms of dementia that make achieving your goals difficult?

- Fatigue
- Pain
- Memory loss
- Mood
- Poor coordination
- Difficulties in communicating

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## What are the tasks that are hard to do because of your dementia symptoms?

- Cleaning
- Shopping
- Gardening
- Participating in family activities
- Personal care
- Participating in the community
- Planning/coordinating my week/day
- Maintaining relationships
- Exercise
- Transport

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## What things would support you to achieve your goals?

- Physiotherapy
- Speech pathology
- Occupational therapy
- Home modifications
- Respite
- Equipment
- Access to social support
- Support coordination
- Assistance with personal care
- Assistance with domestic tasks
- Support for my carer
- Information/education
- Continence support
- Assistive technology

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# APPENDICES

## What community facilities do you engage with?

- Library services/education
- Gym/fitness programs
- Social support /peer groups
- Cultural events
- Recreational activities
- Spiritual groups and services
- Volunteering
- Interest groups
- Meeting with friends/family
- Community programs
- Health and wellbeing
- Shopping and retail

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## What do you want to achieve? (GOALS)

- Maintain my lifestyle
- Improve my lifestyle
- Maintain my relationships
- Participate in the community
- Participate in social activities
- Increase my mobility
- Increase my independence
- Continue/start work or study
- Continue/start volunteering
- Maintain my health and wellbeing

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# APPENDICES

## 3. CARER STATEMENT

These points will help you prepare your Carer Statement before the NDIS meeting.

### General information about the person you care for and your life together

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### How you care for and assist a person with younger onset dementia

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### How you feel about the caring role and the impact it has on yourself and your relationship

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### How your life has changed since the person you care for developed younger onset dementia

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### What you and the person you care for want from the NDIS

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## 4. DAILY SCHEDULE

Time of day	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
<b>Morning</b> 1am – 12pm (NOON)							
<b>Afternoon</b> 12pm (NOON) – 6pm							
<b>Night</b> 6pm – 12am (MIDNIGHT)							

# APPENDICES

## 5. DEVELOPING GOALS

Goal	What I need to achieve this goal
1.	
2.	
3.	
4.	
5.	

## 6. INFORMATION ABOUT YOUNGER ONSET DEMENTIA FOR THE NDIA

The term 'dementia' describes the symptoms of a large group of illnesses which cause a progressive decline in a person's mental functioning. This includes loss of memory, intellect, rationality, social skills and normal emotional reactions, as well as speech and behaviour changes. The symptoms of dementia vary - it is important to understand what symptoms a person experiences and how this impacts on their day-to-day life. For example, a person with dementia may not be able to dress themselves, perform personal care tasks, or prepare a meal without support.

The term 'younger onset dementia' is used to describe any form of dementia diagnosed in people under the age of 65. A person with younger onset dementia will have different needs from an older person with dementia because they are at an earlier stage of their life when they are likely to be more physically and socially active. When diagnosed, a person with younger onset dementia may be in full time employment, raising a family, financially responsible for others, and physically strong and healthy.

The sense of loss for people with younger onset dementia and their family can be enormous. Unplanned loss of income if the person with dementia was working can be a major problem for the family. This can be made worse by the loss of self-esteem that comes if employment ceases, and the loss of a purpose in life. Future plans, perhaps for travel and retirement, or time with children or grandchildren, may no longer be viable. These changes can be significant.

An added challenge can be the attitudes of other people. It can be difficult to accept that a younger person can have dementia, particularly when there are often no obvious physical changes. It may feel like that no-one else understands what is happening. Many people affected by younger onset dementia find that friendships may fade as the dementia progresses.

### **My symptoms of younger onset dementia include:**

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### **How younger onset dementia has changed my life:**

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### **Younger onset dementia affects my life in the following ways:**

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