

# The Carer Pathway

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A guide for carers supporting  
a person transitioning from  
PIR to the NDIS



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An Australian Government Initiative

# About 'The Carer Pathway' guide

This guide is for carers supporting a person who has been with the Partners in Recovery (PIR) program and who may become a participant in the National Disability Insurance Scheme (NDIS).

The word 'carer' is used in this guide to refer to someone who provides unpaid care and support to a family member or friend with mental health challenges. Carers can be partners, parents, children, other family members, friends or neighbours.

The person you support may not think of you as a carer, and you may experience some tension around this, but it does not diminish your importance in providing care and understanding their needs.

The PIR program has provided many carers with the opportunity to be a part of PIR care team meetings and to establish a collaborative relationship with the PIR support facilitator and others in the care team. This is a strong foundation to build upon in supporting a person to become an NDIS participant.

This guide provides an understanding, in summary form, of what kind of support the carer could provide to the PIR participant in their transition to the NDIS. The guide also provides succinct information about some NDIS 'basics' and 'tips' relevant to the carer experience.

*We would like to acknowledge the advice, lived experience of consumers and carers and the contribution of the PIR Carer Support project group in creating this booklet. The group includes Mind Australia, Wellways, Neami National and Tandem.*



# NDIS basics

The NDIS is a new way for people with disability to get the care and supports they need to live a better life. The NDIS provides people with disability choice and flexibility over the supports they receive.

As a carer you can't get an NDIS plan or support package for yourself. The NDIS is there to provide supports for the person with disability, but it can ease the load on carers either directly or indirectly.

The NDIS can support people with psychosocial disability, which is the term used to describe disabilities that may arise from mental health issues. Psychosocial disability is related to the effects on someone's ability to participate fully in life as a result of mental ill-health.

People with significant disability that is likely to be permanent may qualify for NDIS support. The NDIS understands people with a psychosocial disability can experience difficulties which are 'episodic' and vary in 'intensity'. The scheme is designed to be flexible and to meet each participant's individual needs.

Currently, the NDIS is exploring the best possible range of supports for people with psychosocial disability.

The involvement of mental health carers in the NDIS will often be very important to achieving the best outcomes for participants with psychosocial disability. This is because carer involvement can be crucial to ensuring the NDIS support plan is appropriate to the participant's needs.

## Common ways carers could be involved in the NDIS include:

- supporting the participant to apply for the NDIS
- assisting the participant to prepare for the planning meeting and think about their goals and support needs
- attending the planning session with the participant
- being listed in the participant's plan as an informal support
- providing advice on the participant's support needs
- helping the participant manage their NDIS plan
- helping the participant access funded services and supports
- supporting the participant during any review of their support plan.

# The types of support the mental health carer could provide

This section is intended to provide a **practical overview** of the types of support a carer **could provide** to their family member or friend who becomes an NDIS participant.

Different carers will have different roles. The carer's role depends on what the participant wants, what the National Disability Insurance Agency (NDIA) thinks is reasonable, and what the carer feels they can manage.

Where the carer and the person they support (PIR participant) have a good working relationship with the PIR support

facilitator, they may find that together they can accomplish many of the steps in the NDIS process. The PIR support facilitator can guide the process for both the participant and the carer, helping to ensure they feel confident and optimistic, rather than confused and overwhelmed.

It is important to note that how carers are involved in the NDIS process will vary according to the individual participant's circumstances and what is appropriate for the carer. As a carer, you need to consider the level of support that is manageable and sustainable for you to provide now and over time.

Let's consider the types of support the carer **could provide** for different NDIS stages. We'll call this the 'carer pathway', as it is intended to complement the NDIS 'participant pathway'.

**Remember, as a carer, it is up to you to consider how much support you can reasonably provide.**



## Stage 1: Learn about the NDIS

- Check out your community for local NDIS workshops, forums or information sessions.
- Meet with the PIR support facilitator, attend PIR care team meetings, and raise questions about the NDIS.
- Review helpful NDIS resources (websites, brochures, fact sheets, etc.).
- Learn about supported decision making, which happens when one person supports another person to make a decision. Any decision, no matter how big or small, can be supported.
- As you become more informed, ask the person you support if they would like you to assist them in applying for the NDIS.

## Stage 2: Support the access and pre-planning process

- Assist with gathering requested information and reports for the Access Request Form, the first step in applying for the NDIS.
- If the person you support is eligible to become an NDIS participant, commence NDIS pre-planning with the PIR support facilitator.
- Discuss the right supports for the person's disability and circumstances.
- Talk with the person you care for about why your involvement is important for both of you. Discuss how you could assist them through the planning process and to access supports.
- Consider contacting advocacy services, such as a carer organisation or community mental health organisation, to support you as you engage with the NDIA.
- Prepare a written Carer Statement, in readiness for an NDIS planning meeting. The Carer Statement can also be provided to the NDIA in confidence.
- The Carer Statement will include information about the support you provide for the person you care for, how that support impacts you and your family, what you would like to happen in the future, your other responsibilities, and life plans.



## Stage 3: Prepare for and attend the NDIS planning session

- Be familiar with the *My NDIS Pathway* booklet (available on the NDIS website), which describes the first experiences a person will have with the NDIS when developing their individualised plan.
- The Participant Statement and a Carer Checklist may also help in preparing the participant and you, the carer, for the planning session.
- The participant, or even their PIR support facilitator (if they are the NDIS contact person), may be contacted by the NDIA or a Local Area Coordinator to arrange the planning session.
- As a carer, you can attend the NDIS planning session if the person you support would like to have you there. You don't have to formally notify the planner of this in advance.
- A carer may request a separate meeting with the NDIS planner to discuss aspects of their caring role and the supports they provide.
- You may have input into the choice of location for the planning meeting, so that everyone is comfortable. Alternatively, the planning meeting can take place over the phone.
- Contribute information to the planning meeting to the best of your ability, particularly around the participant's support needs. You may choose to bring notes or other summary information for your reference or the planner's reference.
- Discuss the range of supports which may be included in a participant's plan which can assist you, as a carer, in your caring role. Refer to 'Supports carers can access' at the end of this booklet.
- Retain copies of all of your reports and documents for your records.



## Stage 4: Support the implementation of the NDIS Plan

- Once the person you care for has received their approved NDIS plan, familiarise yourself with it and refer to the NDIS Price Guide for more information about the funded support categories.
- Make sure the approved plan is what you agreed and that it matches or is better than the supports the person you care for receives now. If the plan is not right, it may be necessary for the plan to be reviewed by the NDIA.
- If the PIR support facilitator becomes the NDIS support coordinator for the participant's approved plan, work closely with them and the participant to determine how you could support implementation of the plan.
- Collaboration is key, as the participant chooses the right supports and service providers and seeks the carer's input into this process, together with how the financial administration of the plan will be handled.
- The carer may assist the NDIS participant to set up a MyGov account and to access the NDIS portal.
- The NDIS participant may choose for the carer to be the NDIS plan nominee, to act or make decisions on their behalf. The carer may also be a correspondence nominee.
- If the carer is a nominee, the carer can access the participant's NDIS portal.

## Stage 5: Determine your ongoing support

- As a carer you will need to consider the level of your ongoing support in the implementation of the participant's plan.
- You may find yourself in a 'care coordination' capacity — organising support workers and their schedules. Your responsibilities may increase if the participant is hospitalised or their mental health deteriorates.
- You may be the person authorised to approve invoices for support workers and organisations, thus creating an administrative demand on your time.
- Consider the best 'balance' for your ongoing support that is relative to your age, your ability, and your family, professional and community commitments.

# Helpful tips for the carer



Keep track of documents, health records and paperwork which may need to be referenced or produced at meetings.



Ask questions, stand up for yourself, keep an open mind and don't give up.



Create a record of your dealings with the NDIS and ensure you retain all NDIA correspondence.



If you feel overwhelmed, talk it through with someone — the PIR support facilitator, a mental health worker, a friend or an advocate.



Begin your NDIS preparations early and with a sense of optimism. The NDIS is an opportunity for you and the participant to improve your lives.



Challenges will inevitably arise in each stage of the NDIS process, but be confident and positive that they can be resolved.



You may not be an NDIS expert, but you are an expert in caring for the participant.



Be realistic about the level of support you can provide at any stage of the NDIS process, and address issues as they arise.

## Important note:

The NDIS Rules, 'Supports for Participants', states that when the NDIS makes decisions about what supports they will fund for a person with disability, they must ensure this support is sustainable. This means they need to consider what is reasonable to expect families and carers to provide and what the NDIA can do to ensure this support can be provided on an ongoing basis.

<https://www.legislation.gov.au/Details/F2013L01063>



# Supports carers could access

There are a range of supports which *may* be included in a participant's plan to assist carers, either directly or indirectly, in their caring role. For example:

- support coordination for the NDIS participant
- training for carers in how to care for a person with disability or in how to manage certain difficult behaviours
- group or family therapy
- assistance with decision making, daily planning, budgeting and life/transition planning
- respite-like supports (noting these supports will not be called respite in the plan).

## Carer rights in the NDIS

The National Disability Insurance Scheme Act 2013 states carers should:

- have peace of mind that the participant will get the support they need for the rest of their life
- be acknowledged and respected for their role in the life of the participant
- have what they do considered by the NDIA, including what type and amount of support is reasonable for them to provide
- have opportunities, if appropriate, to improve their ability to support the participant.

## Helpful contacts

Carers seeking information, advice and support can contact:

Mind Carer Helpline	<b>1300 554 660</b>
Wellways Helpline	<b>1300 111 500</b>
Tandem — <i>Ready, Steady, NDIS</i>	<b>1800 314 325</b>
Carers Victoria	<b>1800 242 636</b>

# Helpful carer resources:

The following resources may provide carers with a further understanding of their role in supporting someone to be an NDIS participant:

Guide for Mental Health Carers on the NDIS [download pdf guide]

<http://carersaustralia.com.au/storage/guide-for-mental-health-carers-on-the-ndis.pdf>

Mental Health Carer Checklist [download pdf guide] <http://carersaustralia.com.au/storage/mental-health-carer-checklist-to-prepare-for-ndis-assessment-and-planning.pdf>

NDIS First Plan Conversation: Tips for Mental Health Carers, Families and Friends [download pdf fact sheet] [http://tandemcarers.org.au/images/Tandem\\_TipSheet\\_FirstPlanConversation.pdf](http://tandemcarers.org.au/images/Tandem_TipSheet_FirstPlanConversation.pdf)

My NDIS Pathway [download pdf booklet] [www.ndis.gov.au/html/sites/default/files/My-NDIS%20-Pathway.pdf](http://www.ndis.gov.au/html/sites/default/files/My-NDIS%20-Pathway.pdf)

Reimagine Today (website) [www.reimagine.today](http://www.reimagine.today)

NDIS Snapshots for Carers [www.everythingcarers.org.au/resources/ndis-resources/ndis-snapshots-for-carers/](http://www.everythingcarers.org.au/resources/ndis-resources/ndis-snapshots-for-carers/)

Disability Advocacy Finder <https://disabilityadvocacyfinder.dss.gov.au>

## Acknowledgements:

This guide has been compiled and written with reference to a range of NDIS materials available on websites including:

National Disability Insurance Scheme: [www.ndis.gov.au](http://www.ndis.gov.au)

Mental Health Australia: [www.mhaustralia.org](http://www.mhaustralia.org)

Reimagine Mental Health, My Recovery and the NDIS: [www.reimagine.today](http://www.reimagine.today)

Carers Australia NSW: [www.carersnsw.org.au](http://www.carersnsw.org.au)

New South Wales Government National Disability Insurance Scheme: [www.ndis.nsw.gov.au](http://www.ndis.nsw.gov.au)

Carers Australia VIC: [www.carersvictoria.org.au](http://www.carersvictoria.org.au)

Tandem: [www.tandemcarers.org.au](http://www.tandemcarers.org.au)

Mental Health Carers NSW: [www.mentalhealthcarersnsw.org](http://www.mentalhealthcarersnsw.org)

NDIS Victoria [www.vic.gov.au/ndis.html](http://www.vic.gov.au/ndis.html)

We gratefully acknowledge information contained on these websites — especially fact sheets, guides, snapshots and templates — in the development of this carer brochure.

# Notes:

*Information contained in this booklet is current at the time of publication [March 2018].*

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