

National Disability Insurance Scheme (NDIS)

**Pre-Planning Resource
Motor Neurone Disease**



For people living with motor neurone disease



This planning resource is designed to assist you identify the areas of your life the NDIS will need to consider when developing your NDIS plan.

National Disability Insurance Scheme (NDIS) Pre-Planning Resource for people living with motor neurone disease

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Publication feedback

We welcome suggestions from people using this document so that it can be improved over time.

Publication disclaimer

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The information in this booklet is provided on the basis that all people accessing this resource undertake responsibility for assessing the relevance and accuracy of its content for their own purposes.

Additional resources and information can be found on the NSW Government website <http://ndis.nsw.gov.au/> and the NDIS website <https://www.ndis.gov.au/>

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**“We encourage you to be as prepared as possible
for your NDIS planning meeting.”**

Alexandra Matouk | Team Leader - Coordination of Support
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The National Disability Insurance Scheme (NDIS)

The NDIS is a new model of funding for disability services in Australia and is designed to give people with disability (participants) choice and control over their disability supports and services. The NDIS replaces ADHC funding which you may have previously received for your services.

The NDIS provides funding only. It does not provide direct services. A person's NDIS funding is detailed in their NDIS plan. The NDIS plan also includes information about the supports and services the NDIS funding covers. Each participant chooses the service providers to provide the supports listed in their NDIS plan.

Participants can log in to the NDIS secure website, the MyPlace Portal, to see their plan and how much NDIS funding they have at any given time. The NDIS provides participants with information about how to do this once the plan is approved.

An NDIS plan

An NDIS plan has several sections called support areas. The MND NSW Pre-Planning Resource is divided into similar support areas for you to work through. It also includes information on NDIS processes, timelines for new participants and a glossary.

It is important that you take time to read this information thoroughly and complete the information in each section **before** your planning meeting. If you need assistance completing the sections or have any questions, please contact your MND Advisor or contact the MND NSW Info Line ph. 1800 777 175.

When you are contacted by the NDIS planner or LAC

When you are contacted by the NDIS planner or local area coordinator (LAC) to arrange your planning meeting (or information gathering session), we strongly recommend the following actions:

1. **Advise** them immediately that you have **motor neurone disease** and ask if they have an understanding of the condition (they may not).
2. Ask for your planning meeting to occur **face-to-face**. You do not have to accept a phone meeting; phone meetings are not usually effective for people with MND.
3. **If applicable, advise** them that you have **high medical support needs** and ensure that they understand that before commencing the planning meeting.
4. **Contact** your **MND Advisor**, they can assist with additional pre-planning and may be available to attend your planning meeting, though this is not always possible.
5. **Prepare** for your meeting. This resource will assist you in your preparation.

Most NDIS plans are designed to last 12 months

Most NDIS plans are designed to last 12 months. A plan review will then take place to ensure the funding still meets your needs. This works well for most people who do not have rapidly progressing neurological disorders. However, people living with MND may experience multiple changes to their needs over the course of 12 months.

We recommend you ask for as much flexibility as possible in your plan (the planner should include funding for supports that you might not need now, but may need in the near future) so your needs can be met as they change.

Using this resource

The MND NSW NDIS Pre-Planning Resource is designed to assist you identify the areas of your life the NDIS will need to consider when developing your NDIS Plan.

Sections in this resource have been designed to assist you **prepare** for your planning meeting. Complete the sections marked  **before** your planning meeting.

Section 1

Services and supports I receive now

Section 2

Services and supports I need to remain independent in my home and the community

- Home Care Supports and Consumables
- Community Access and Social Participation
- Assistive Technology (Equipment and Communication Aids)
- Improved Daily Living (Therapies/Allied Health)
- Home and Vehicle Modifications
- Support Coordination - coordinating your NDIS supports

Section 3

Managing My NDIS Funding

Section 4

Other notes and considerations

Section 1 Services and supports I receive now

 Use this page and the page following to list all services and supports you are currently receiving. These may include the following services:

- Personal care
- Domestic assistance (cleaning/washing)
- Shopping assistance
- Meal preparation
- Community access (outings)
- Social support (companionship)
- Respite
- Assistive technology (equipment and aids such as shower chair, manual wheelchair)
- Other _____

Your current services and supports may be provided by government, paid service providers including doctors, allied health professionals (such as an occupational therapist, physiotherapist or speech pathologist), community care workers and domestic assistance workers or others including family, friends and neighbours.

The NDIS has an obligation to continue funding your reasonable and necessary disability related supports, so it is essential that you let them know about **all of the supports you are currently receiving** and the number of hours for each.

Also note if these supports **are not meeting your needs**.

It is important to communicate this clearly to the NDIS planner, including additional services or supports you feel you need in order to have the best quality of life possible.

Section 1 Services and supports I receive now

Day	Morning	Afternoon	Evening	Night	Unmet Needs/Notes
 Monday					
 Tuesday					
 Wednesday					
 Thursday					
 Friday					
 Saturday					
 Sunday					

Section 2 Services and supports I need to remain independent in my home and the community

In this section provide detailed information about the particular needs you have now. Also include needs you think you might have during the next 12 months because most NDIS plans are designed to last 12 months.

2.1 Home Care Supports and Consumables

The NDIS will fund 'reasonable and necessary' supports to help you remain independent in your home and the community. These may include paid carers and support workers to assist you with daily tasks such as washing, dressing, preparing meals, cleaning your home, maintaining your garden or developing new skills. The NDIS often does not refer to 'respite' specifically, but sufficient funded in home supports will ensure family and informal carers have the opportunity to take a break from their caring role when needed.

The NDIS will also fund 'consumable' items related to your disability such as continence aids (pads, wipes, gloves etc), non-invasive ventilation (NIV) tubes and masks and home enteral nutrition (HEN) items.

Think about

What home care supports and services am I currently receiving?

Do they meet my needs now?

Will they meet my needs for the next 12 months?

Are my current providers NDIS approved and can I continue to work with them when I have NDIS funding?

Do I have any reports from health professionals about my home care needs? Do my current services offer enough support so my family/informal carers can take regular breaks and maintain their own independence?

Do I need to purchase gloves, NIV masks, Hen tubes or similar on a regular basis?

Do I get these items from an NDIS approved supplier?

Sample Goal

To maintain safety, independence and comfort at home and maintain the sustainability of my informal supports.

2.1 My Home Care Supports and Consumables

 **My Goal**

 **My current supports**

 **My current unmet needs**

 **My additional needs**
In the next 12 months I will need...

2.2 Community Access and Social Participation

The NDIS will fund supports to help you stay active in the community. This includes ensuring you can continue to interact with your community and engage with essential services and supports outside of your home.

Think about

What things do you do outside your home/in the community now?

What does your disability stop you doing in the community now?

What things would you like to do outside your home/in the community in the future?

If you already have Community Access and Social Participation supports in place, are the providers NDIS approved?

Do you need funding for more support in this area?

What would help?

paid carer

modified vehicle

wheelchair

personal alarm

communication aid

transport funding

Sample Goal

To continue to be able to access my community and pursue my interests.

2.2 My Community Access and Social Participation

 **My Goal**

 **My current supports**

 **My current unmet needs**

 **My additional needs**
In the next 12 months I will need...

2.3 Assistive Technology (Equipment and Communication Aids)

The NDIS will fund the repair and maintenance of your existing disability specific assistive technology (including equipment and communication aids). The NDIS will also fund the hire or purchase of assistive technology that meets the criteria of 'reasonable and necessary' and has been prescribed by a health professional, such as an occupational therapist, physiotherapist or speech pathologist.

Think about

What equipment related to my disability do I use every day?

Who supplied the equipment (did you buy it? Is it on loan from FlexEquip? Is it from Enable NSW?)

Does the equipment meet my needs now?

Will the equipment meet my needs for the next 12 months?

Is there some equipment or communication technology that I need now but do not have?

What activities do I use my equipment for?

Does my equipment need repair and/or regular maintenance?

Are there things I want to achieve or maintain (goals) that require me to have different/more equipment?

Sample Goal

To maintain my independence in all areas of life and my ability to communicate with my family and friends.

“If you currently have equipment provided by *FlexEquip* and wish to continue using it, *the NDIS will need to provide funding in your plan to cover the ongoing hire cost of your items. Your MND Advisor can tell you about FlexEquip’s equipment options and provide you with a list of your current equipment and hire cost for you to give to your NDIS planner to ensure that funding for this is included in your plan.*”

Maree Hibbert | FlexEquip Coordinator
FlexEquip, a service of MND NSW

2.3 My Assistive Technology (Equipment and Communication Aids)

My Goal

My current equipment

Include items currently provided by FlexEquip and other items you have

My current unmet needs

My additional needs

An occupational therapist can assess you and make equipment recommendations and prescriptions.

In the next 12 months I will need...

2.4 Improved Daily Living (Therapies/Allied Health)

The NDIS will fund 'reasonable and necessary' therapeutic assessments, reports and interventions related to the impact of your disability based on your functional ability.

These may include **occupational therapy, physiotherapy, speech therapy** and **dietetics** amongst others.

The NDIS will not fund therapeutic interventions that are related to the acute medical aspects of your disability, these are the responsibility of the Health system.

Think about

What therapies do I currently access?

How often do I need therapeutic interventions?

What assessments and reports do I need and how often are these needed?

Who provides these - are they an NDIS approved provider?

Will that provider continue to work with me when I have NDIS funding?

What areas of my life are improved by therapeutic interventions?

Do I need a therapist for all my sessions, or can a support worker be trained to do some of my therapies with me?

Are there therapies that I need that I have been unable to access for whatever reason?

Is the health professional who prescribes my equipment going to keep working with me when I have NDIS funding? How many hours are needed for this?

Sample Goal

To maintain my mobility, and improve comfort and wellbeing.

2.4 My Improved Daily Living (Therapies/Allied Health)

 **My Goal**

 **My current therapies, providers and frequency**

 **My current unmet needs**

 **My additional needs**
In the next 12 months I will need...

2.5 Home and Vehicle Modifications

The NDIS may fund 'reasonable and necessary' modifications to your home that have been prescribed by an occupational therapist so you can continue to move around it safely and access the areas you need to use.

The NDIS may fund 'reasonable and necessary' modifications to a vehicle that have been prescribed by an occupational therapist to assist you to maintain ongoing access to the community. Vehicles must meet the NDIS criteria in terms of suitability for modification.

Think about

What modifications are already in place in my home?

Do they meet my current needs?

Will they meet my needs for the next 12 months?

What other changes might I need to make to my home so I can move around safely in the future?

Can I use my own vehicle safely for the next 12 months?

What alternative transport options are available to me?

Where do I want to travel to, how often, and who will be with me?

Would I be able to buy a new car if mine was not suitable for modifying?

Sample Goal

To maintain my safety and independence in my home and to continue contributing to and accessing the community.

2.5 My Home and Vehicle Modifications

 **My Goal**

 **My current modification/transport methods**

 **My current unmet needs**

 **My additional needs**
In the next 12 months I will need...

2.6 Support Coordination - coordinating your NDIS supports

The NDIS considers it reasonable and necessary to fund **Support Coordination** for people with ‘*conditions of a degenerative nature*’ and those with ‘*severe disability requiring multiple support and services*’.

This means people living with MND can have **assistance** in coordinating their funded supports (service providers), informal supports (family and friends) and mainstream supports (health care and medical) if necessary.

You may have had a case manager in the past - this person may not transition with you to the NDIS, so the alternative option is to have an NDIS funded coordinator of supports.

A **coordinator of supports** can assist you to:

- navigate the NDIS
- understand how you can use your funding flexibly
- identify suitable providers for services and supports that you may need
- resolve issues related to your plan.

It is important that if you want comprehensive, ongoing assistance with coordinating your plan, you ask the NDIS planner at your planning meeting to include Support Coordination funding in your plan.

 **My notes**

MND NSW is an NDIS approved provider of support coordination.

If you would like to know more about support coordination with MND NSW, you can speak to your MND Advisor, or call 1800 777 175.

Section 3 Managing my NDIS funding

There are three options for managing your NDIS funding.

- **NDIS MANAGED:** This means the NDIS can manage the funds on your behalf and so you can only choose NDIS approved providers to provide your services. These are providers who the NDIS have assessed and who have agreed to set rates and prices for services provided under the NDIS, meaning they cannot charge more than the set rate for services. NDIS approved providers bill the NDIS directly for your services, and you will see your funding balances change on the NDIS MyPlace portal as they do so. When using this method you do not have to worry about invoices or payments, but you are restricted as to who can provide your services.
- **SELF MANAGED:** This means you are responsible for receiving and paying invoices from your service providers, and then reimburse yourself from your NDIS funds using the MyPlace Portal. This method allows you to choose providers who are not NDIS approved and who may charge higher rates for standard services than those set out in the NDIS guidelines. This method gives you more flexibility, but requires more work from you, the participant.
- **PLAN MANAGED:** This means the NDIS pays a plan management agency to act as financial manager of your funds. In this case, the providers you choose may not be NDIS approved, however they must still agree not to charge more than the maximum price for their particular service as set out by the NDIS. Your service providers will send their invoices to the plan management provider who pays them, then claims the funds back from your plan. This method offers you more flexibility than an NDIS managed plan, and is less work than self-managing (you don't have to pay invoices).

As your plan will contain funding grouped into 'budgets' you can even choose a combination of these methods to manage your plan. For example, you may choose to self-manage your *Improved Daily Living* budget which covers allied health but keep the rest of your plan NDIS managed. This would allow you to continue to see a physiotherapist who is not an NDIS approved provider and to engage NDIS approved providers for everything else.

You can discuss the best option for you with your NDIS planner. Whichever option you choose, you must tell the NDIS representative at your planning meeting. If you do not make a specific choice, the default option is always NDIS managed.

This means if you currently use non-NDIS approved providers, you will have to stop using them and switch to NDIS approved providers.

 **My notes**

Section 4 Other notes and considerations

It is recommended that you provide the NDIS representative soft copies (computer files) of your most recent health and/or allied health reports if you have them available. If you are visiting your health or allied health professional or MND clinic before your NDIS planning meeting, you can ask them for a short report that includes recommendations for equipment or support you may need during the next 12 months.

 **My notes**

Your NDIS Journey: What to expect

Are you currently receiving NSW Government funded disability supports (home care, community access, respite etc.)?

YES	NO
<ul style="list-style-type: none">You will automatically be assessed eligible to enter the Scheme.You should expect a call from an NDIS representative to arrange a planning conversation (this may also be referred to as a planning meeting or information gathering session).	<ul style="list-style-type: none">You will need to call National Disability Insurance Scheme (NDIS) on 1800 800 110 and request an Access Request Form and return it to them. The NDIS will assess your request and contact you if you are eligible to enter the Scheme. <hr/> <ul style="list-style-type: none">If you have MND and are under 65 years of age, you will be eligible but may need to provide supporting evidence of your disability. <hr/> <ul style="list-style-type: none">Once accepted to the Scheme, you will receive a letter from the NDIS confirming this, followed-up by a call from an NDIS representative to arrange a planning conversation (this may also be referred to as a planning meeting or information gathering session).

What to Do: When the NDIS representative calls you

1

- The NDIS representative who calls you may be:
 - a planner from the NDIA (the agency that runs the NDIS)
 - a contractor known as a Local Area Coordinator (LAC). Local Area Coordinators are employed by organisations such as St. Vincent de Paul, Social Futures or Uniting, all of whom have contracts to work for the NDIA.

2

- The NDIS representative who calls you may not know that you have MND. It is very important that you tell them you have MND at the beginning of the call, and then request that your planning conversation happen in a face-to-face meeting, not over the phone.
- If appropriate, you should also state that you have high medical support needs as a result of your MND (especially if you use NIV or have a PEG).

3

- The NDIS representative should then schedule your face-to-face planning conversation for a time and place (preferably your home) that works for you. You are allowed to have support people present at your meeting; these can be family members, friends, carers, advocates, your MND Advisor or a mixture of all the above – it's up to you.

What to Do: Before your planning conversation



- Before the planning conversation, you will need to prepare. Think about all the supports you receive now and may need in the next 12 months that the NDIS will have to provide funding for.



- It is also a good idea to speak to your current service providers, allied health professionals and medical team to get the most up to date information about your support needs before the meeting.



- MND NSW can provide you with pre-planning support through your MND Advisor and our NDIS pre-planning resources. Contact your MND Advisor or MND NSW ph. 1800 777 175 to find out more.



- If you have equipment in place from FlexEquip, you will need to call your MND Advisor and let them know that your planning conversation is happening soon. Your MND Advisor will provide you with the essential information about your equipment that you will need to give to the NDIS representative to ensure you get funding to continue using this equipment.

What to Do: During your Planning Conversation



- Tell the NDIS representative about all the different ways your disability affects your life, and the life of your primary carers (partner/family/friends).
- Tell the NDIS representative about all the supports and services you are currently receiving, and any supports or services that you are likely to need in the next 12 months.



- Give the NDIS representative copies of any pre-planning resources you have completed and any health reports that are current (less than 6 months old).
- Ask how long you can expect to wait before your plan is ready (it is usually between three days and two weeks).



- Ask the NDIS representative for their contact details before they leave, so you can follow up with them if there are any issues with your finished plan, or if you think of anything after the meeting that you need to advise them about.

What to Do: When you get your NDIS plan



- Read about how to use the MyPlace portal to access your plan at <https://www.ndis.gov.au/participant-portal-user-guide>.
- Read through your NDIS plan and look for a budget called support coordination. The support coordination budget will look something like this:

Support Area:	Support coordination
Budget:	\$9596.08
Details:	104 hours Coordination of Supports to be used flexibly to assist with the coordination of formal, informal, mainstream and funded supports to achieve the stated goals in this plan.
How will the supports be paid:	NDIS will pay my support provider directly for these supports

DOES your Plan include a budget for support coordination?

YES	NO
<ul style="list-style-type: none"> • This means the NDIS has given you funding to pay a professional coordinator to help you understand and enact (use) your plan. • The NDIS will call you to ask who you would like to provide this service to you. If you would like MND NSW to provide your support coordination, you can tell the NDIS and they will refer you to MND NSW. • If you would like another organisation to provide your support coordination (for example if MND NSW does not offer this service in your area), you can tell the NDIS and they will refer you to your chosen provider. • If you do not have a preference for who provides your support coordination, the NDIS will randomly select a provider on your behalf and will refer you to them. • Whichever option you choose, the provider will call you within five days of receiving your referral from the NDIS to get started with enacting your plan. 	<ul style="list-style-type: none"> • Instead of a support coordinator, you will have access to a local area coordinator to help you understand and enact (use) your plan. • Your local area coordinator may have facilitated your planning conversation. • You can contact the local area coordinator to ask for assistance with your new plan. • Local area coordinators provide a lower level of assistance than support coordinators, and can only help you for a short time. • It is important that if you feel you should have more assistance in this area, ask your local area coordinator to process a plan review on your behalf specifically requesting funding for support coordination.

NDIS Acronyms and phrases

SOURCE: <http://ndis.nsw.gov.au>

National Disability Insurance Scheme (NDIS)

The NDIS is a scheme that will operate across Australia. It supports people with disability to:

- achieve their goals
- take part in daily life
- choose their own supports and services.

National Disability Insurance Agency (NDIA)

It is the NDIA's job to manage the NDIS. They support people with disability to:

- achieve their goals
- take part in daily life.

Access request

An access request is how you apply for, and take part in, the NDIS.

Approved plan

If you take part in the NDIS, you will have an approved plan that includes:

- the goals you want to achieve
- the supports you need to achieve your goal.

Continuity of support

Continuity of support means that you will continue to get the supports and outcomes you were getting before the NDIS started.

Efficient price

An efficient price is worked out by the NDIA for the supports in your plan. It shows the most you should have to pay for each support.

Full scheme

The full scheme will take place when the NDIS is rolled out across all of NSW on 1 July 2018.

Functional impairment

You can take part in the NDIS if you have a disability that will last for your whole life and need help in your day to day life. This means you may need support to:

- communicate
- move or get around
- take care of yourself
- manage yourself through the day.

Individualised funding

Your NDIS plan will include funding provided to you for the supports you need. You can choose:

- what supports and services you will use
- who will provide you with those supports and services.

Lifelong support

You can take part in the NDIS if you have a disability that will last your whole life. The NDIS will look at ways to support you now and into the future. Those supports can change as you change.

Local Area Coordinator (LAC)

These are people who work in your local community. Their job is to:

- help you and the NDIA to prepare your first plan.
- help the community think about better ways to include people with disability
- support people with disability to be more independent
- help break down barriers people with disability face.

Management of funding

Management of funding is a way of taking care of how you pay for the supports or services you need. This includes:

- paying your service providers
- processing claims for money you spend
- providing you with monthly statements
- claiming payments from the NDIA.

My First Plan

If you take part in the NDIS you will get a first plan that may include the supports and services you have now. It will last for 12 months. It will also include:

- more support if you need it
- a place to show your goals.

It might include supports you get from:

- family
- friends
- doctors
- school
- paid service providers.

NDIS Access Checklist

The NDIS Access Checklist is a tool you can use to work out if you might be able to use the NDIS. You can find it on the NDIS website ndis.gov.au

NDIA Planner

These are people who work for the NDIA.

They help people get their plans ready.

Your plan will explain:

- what your goals are
- what services you will need to achieve your goals.

NDIS registered service providers

The NDIA registers people or organisations who offer support or products to people with disability.

The NDIA makes sure these people or organisations can deliver the supports they are registered to provide.

Plan Nominee

If you choose someone to act on your behalf they are called your nominee. This can be:

- your guardian
- your carer
- another person you choose to support you.

You might have a nominee if you can't make decisions for yourself.

Participant

A person with disability who has an NDIS plan.

Participant phasing

The NDIS will start at different times in NSW for people with disability depending on:

- where you live
- what services you need.

Person-centred approach

You are at the centre of any decision making about what you need.

Self-direction

You make all the decisions about the supports and services you choose and use.

Your family or your carer might help you.

USEFUL ACRONYMS

LAC: Local Area Coordinator

NIV: Non-invasive ventilation

HEN: Home enteral nutrition

ADHC: NSW Dept. of Ageing Disability and HomeCare

CoS: Coordination of Support