



My Life with HD

NDIS Series - Pre-planning Workbook



Being prepared benefits you

This workbook has been written for people with Huntington's Disease (HD) who are eligible to be an **NDIS participant**.

This version of the workbook is for people affected by HD to complete with the assistance of their support team.

Its purpose is to help you to prepare for your NDIS planning meetings.

It provides:

- A *brief* explanation of the NDIS planning process and its language
- Room for you to write down the supports and services you use now (page 9)
- Scope for you to think about what you would like changed to make your life easier (page 29)
- Space for you to consider future steps to take to bring these changes into your life (page 37)
- All the exercises above will allow you to have conversations about the NDIS that are right for you.

ACKNOWLEDGEMENTS

We would like to thank the:

NSW Department of Family & Community Services; Ageing, Disability and Home Care, for funding the creation of this resource; and

Dedicated staff at the Huntington Disease Service, Westmead Hospital and

The information in this workbook is current at December 2017.

Huntington's NSW & ACT will continue to review and update this workbook as required.

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What is the National Disability Insurance Scheme (NDIS)?

- The NDIS is a new way of funding support for you so you can live the life you want.
- The NDIS is based on a personalised support plan that changes when your needs and goals change, throughout your lifetime.
- You choose how, when, where and by whom your supports are provided.

The NDIS provides individualised care and support for people with Huntington's disease who are under the age of 65 years

What is the NDIA and what does it do?

The National Disability Insurance Agency (NDIA) is an independent statutory agency, whose role is to implement the National Disability Insurance Scheme (NDIS), which will support a better life for hundreds of thousands of Australians with a significant and permanent disability and their families and carers.

The NDIA registers new **NDIS participants**, completes, approves and reviews **NDIS plans**. The NDIA is also responsible for conducting appeals if your plan is not meeting your support needs.

How do you access the NDIS?

You need to meet the following criteria;

- Have a confirmed Huntington's disease diagnosis;
- Be aged less than 65;
- Be an Australian citizen or hold a permanent visa or a Protected Special Category visa

If this is you, then:

GET YOUR NAME DOWN AS A PARTICIPANT

Ring the **NDIA** on 1800 800 110 and ask them to post you an **Access Request Form**.



Tips at this point

1. **Your number 1 priority is to take care of yourself.**

Navigating the NDIS can be a long and confusing process. To avoid becoming overwhelmed seek help as soon as you need it.

2. **Collect your evidence**

- A letter from your GP (or specialist) confirming your HD diagnosis
- Call your **HD Service key worker** on 8890 9960 or 8890 6699 (Hunter region call 4922 3076)
 - ◇ Advise them you've requested an **Access Request Form** to be posted.
 - ◇ Ask them to bring together your assessments from the Clinical Neuropsychologist; Allied Health: Speech Pathologist, Dietician, Physiotherapist, Occupational Therapist; and Social Worker.

3. **Look out for your Access Request Form in your mail box**

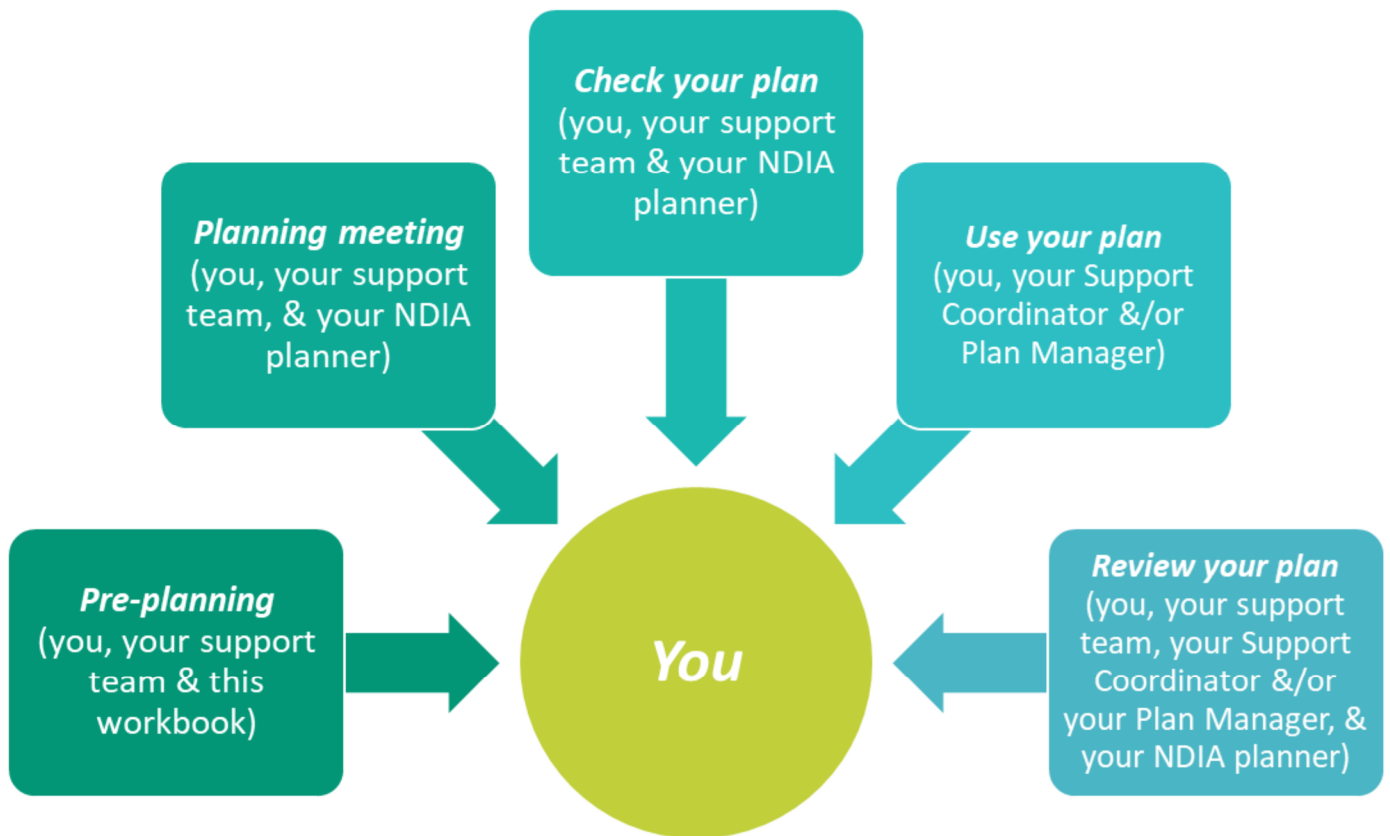
When you receive the forms call your **HD Service key worker** on 8890 9960 or 8890 6699 (Hunter region call 4922 3076). This is the best person to help you complete these forms. They will use the right terminology and obtain the right evidence to support your application.

The NDIS website (<https://www.ndis.gov.au>) has many factsheets and videos to help you understand *what* the scheme is and *how* you can become an **NDIS participant**.

A snapshot of the resources we think are best in explaining this can be found at the end of this workbook in the **NDIS fact sheets and videos we think you need to be aware of** section, see page 57.

If you have further questions regarding the NDIS you can call them on 1800 800 110.

What is the NDIS process & who is involved?



Pre-planning

Pre-planning is preparing for your first **NDIS planning meeting**

1. Pre-read the NDIS resources on this webpage so your familiar with the aims of the **NDIS planning meeting** <https://www.ndis.gov.au/participants/firstplan.html>
2. Use this workbook, with the help of your support team, to plan for your meeting.

Planning meeting

The aims of your first **NDIS planning meeting** are, for you and your **NDIS planner**, to:

- Understand, and accurately record, how you are living now;
- Identify the **supports** you need **immediately**;
- Begin your thinking around any goals you want to achieve

An **NDIA planner** will phone you to organise your first **NDIS planning meeting**.



Tips at this point

1. **Request to have a meeting in your home, face to face.**
Meetings over the phone make it difficult to relay the complex support needs of people with HD.
2. **Ask** your support team to attend your meeting. This might include:
 - a. **carer** or guardian;
 - b. your **HD Service key worker**; and/or
 - c. important family members.
3. **Ask** the **NDIS planner** to do some research on HD before they meet you.
4. **At the meeting:**
 - a. **Share this workbook** with the **NDIA planner**. It can be used as your **Participation Statement**;
 - b. **Ask** for **Support Coordination**. They become your personal NDIS assistant, they will do all the leg work to find you service and support options and then you make the final decisions.



Your **HD Service key worker** is critical in helping you find the most appropriate **Support Coordination** contact.

Check your plan

Your **Support Coordinator** will phone you to organise to meet you.

The aims of your first **Support Coordination meeting** are, for your **Support Coordinator**, to:

- get to know you, your support team, your needs, and your **NDIS plan**;
- set up a service agreement between you and them;
- understand how you would like to be communicated with;
- ensure your **NDIS planning** reflects what was discussed in your **NDIS planning meeting**;
- train you and your support team on how to use **myplace** (NDIS participant portal).



Tips at this point

1. **Request to have a meeting in your home, face to face.**

Meetings over the phone make it difficult to relay the complex support needs of people with HD.

2. **Ask** your support team to attend your meeting. This might include:

- a. **carer** or guardian;
- b. your **HD Service key worker**; and/or
- c. important family members.

3. **Ask** your **Support Coordinator** to do some research on HD before they meet you.

4. **Share this workbook** with your **Support Coordinator**. It will assist them in understanding your needs.

5. **Ask** your **HD Service key worker** to review the adequacy of your **NDIS plan**.

You have 28 days to lodge an appeal if it is seen as inadequate.

Use your plan

- Your **NDIS plan** is for a 12 month period. Once your plan is approved, you can choose your service providers.
- Your **Support Coordinator** can assist you to find service and support options and with setting up service agreements and making any bookings.
- If you are unhappy with any service or support you can change providers. If you require assistance with this your **Support Coordinator** can assist you in making adjustments; changing services and seeking alternatives.

Review your plan

A review of your **NDIS plan** can be undertaken at any stage. If your circumstances have changed or your plan is seen as being inadequate, contact your **Support Coordinator** to assist you with reviewing your plan.

Your **NDIS plan** will automatically go into a review cycle one month before its anniversary date. Your **Support Coordinator** will phone you to organise a new planning meeting. Request a Review workbook so you can complete pre-planning activities.

Overcoming obstacles with my NDIS plan

There may be supports missing from the **NDIS plan** you receive.

This could be because:

- Your **NDIS plan** does not reflect everything you need right now;
- You have not received your supports at the time you need them;
- Your needs or support have not changed since your **NDIS planning meeting**; or
- You disagree with a decision made by the **NDIA** regarding your eligibility for a support or service.

Feedback and Appeals

There is a pathway that allows you to investigate any concerns you may encounter.

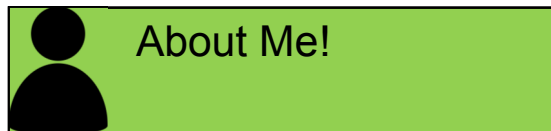
Consider the following to assist you

- Contact your **NDIS Support Coordinator** or **NDIS planner** to discuss first
- Change of circumstances – information <https://www.ndis.gov.au/participants/understanding-your-plan-and-supports/change-circumstances.html> and
- Change of circumstances – application form <https://www.ndis.gov.au/medias/documents/h42/haa/8802538061854/change-of-circumstances.pdf>
- NDIS Appeal process - *Review of a Decision* - <https://www.ndis.gov.au/medias/documents/h7a/h60/8800158679070/Factsheet-Internal-Review-of-a-Decision.pdf>
- NDIS complaints processes - <https://ndis.gov.au/about-us/contact-us/feedback-complaints.html>

How to use this HD NDIS series workbook

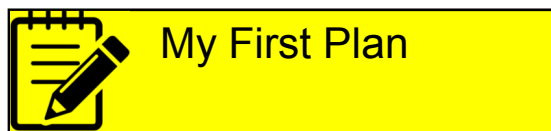
This workbook is for you to record information specifically about your circumstances.

There are 4 sections:



In this section, you write down:

- Contact information about yourself and your 'go to person'
- Where you live and the people you live with
- If important circumstances apply to you
- What's important to you, what things you need to feel healthy and your likes and dislikes
- What are your aspirations i.e. short and long term goals.

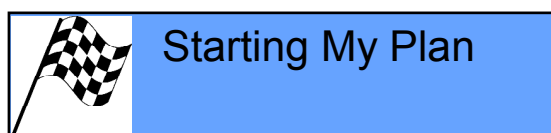


In this section, you write down the detail for what is happening now:

- What you do in daily life, who helps you, what they do, and for how long.
- What supports and parts of your life that are working for you.
- What could be improved, changed or do you require more supports.
- The transport you use, who helps you and what it costs you
- What equipment and aids you use
- What consumable products you use
- What things make your day difficult.

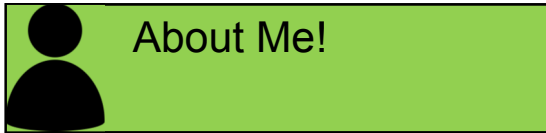
Then, you write down the detail for what you would like to make your life easier:

- Changes and supports you need across your **Life Domains**
- What you would like to achieve over the next 12 months and long term and
- What supports you will need to achieve this.



In this section, you write down:

- The detail of your first **NDIS plan**, your **budget**, your **service providers**, your notes, and to-do lists
- Details of any plan reviews you've requested.



My Personal Profile

My Name: _____

Birthdate: ____ / ____ / ____

My Address: _____

My age: _____

Post code: _____

How to contact me:

Phone: _____ Mobile: _____

Email: _____

My 'go to person': *the person who helps or supports me the most*

Name: _____

Phone: _____


Email: _____

I was diagnosed on: ____ / ____ / ____ by: _____

Profession: _____ Phone: _____

		Record Details	
<input type="checkbox"/>	I have a job		
<input type="checkbox"/>	I have a current driver's license		
<input type="checkbox"/>	I have ambulance cover		
<input type="checkbox"/>	I have a Health/concession card		
<input type="checkbox"/>	I have private health insurance		
<input type="checkbox"/>	I am on a pension		
<input type="checkbox"/>	I receive a mobility allowance		
<input type="checkbox"/>	I am registered with the Isolated Patients Travel & Accommodation Assistance Scheme (IPTAAS)		
<input type="checkbox"/>	I have a Power of Attorney		
<input type="checkbox"/>	I have appointed an Enduring Guardian		
<input type="checkbox"/>	I have prepared a Will		

More
about
me (tick
those
boxes

About Me!

Me on a page

Tell the NDIS Planner all about you

As at date: / /

Living arrangements
What is important to me
I need to do these things to feel healthy

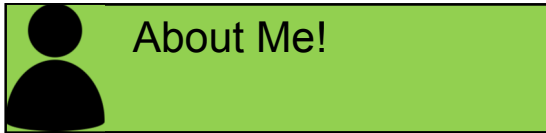


About Me!

I like

I dislike

My aspirations i.e. short and long term goals
These are the things I would like to be able to do.



Me on a page sample

As at date: 01/11/2017

Living arrangements

I live in a rented house with my partner and our 3 kids.

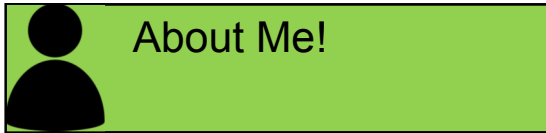
We are on a property more than 100 kms away from medical support.

What is important to me

- *Being well groomed*
- *Be supported with decisions regarding my health, home and family*
- *Spending time with my family and friends*
- *To remain living at home for as long as I am able*
- *Giving my partner a break from caring once a week*
- *Attending important occasions involving my kids*
- *To feel I'm connected to people outside of my home*
- *Being safe in my own home*
- *To maintain independence for as long as possible*
- *Meeting and talking to other people*
- *Talk to me in a respectful way*

I need to do these things to feel healthy

- *Exercising every day*
- *Take my medications*
- *Attend my medical and allied health appointments*
- *Socialise with people who understand HD*
- *Staying active in my local community*

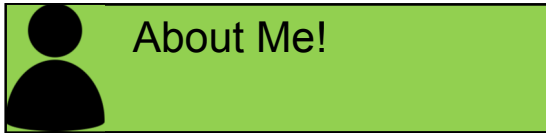


Me on a page *sample*

I like
<ul style="list-style-type: none">• <i>Meeting new people</i>• <i>Going on outings like to the movies, the zoo, the theatre the football or car racing.</i>• <i>Being creative and artistic</i>• <i>1960s music</i>• <i>Swimming</i>• <i>Playing with my kids and pets</i>• <i>Going out for a coffee, for a walk to my favourite spot, or for a drive.</i>
I dislike
<ul style="list-style-type: none">• <i>Loud noises</i>• <i>Large crowds</i>• <i>Snakes</i>
My aspirations i.e. short and long term goals
<ul style="list-style-type: none">• <i>Visit my brother in Queensland twice a year</i>• <i>Continue to holiday with my family once a year</i>



'Me on a page' notes



My Support Teams

Think about the important people in your life and how they help you.

These people fall into two different categories under the NDIS: **informal and formal supports**.

Informal supports

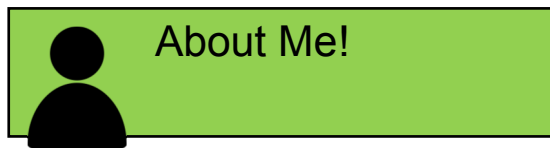
Name	Relationship	How they help me	How often they help

Are people who help you without receiving payment.

Formal supports

Are people who help you for payment.

Name	Relationship	How they help me	How often they help



People looking after my health and wellbeing

Name	Relationship	Phone	How often they help
	Counsellor		
	Dietician		
	General Practitioner (GP)		
	Hospital		
	Neurologist		
	Occupational therapist (OT)		
	Personal trainer/ Exercise physiologist		
	Pharmacist		
	Physiotherapist		
	Psychiatrist		
	Psychologist		
	Social worker		
	Speech pathologist		

People looking after my affairs

Name	Relationship	Phone	How often they help
	Financial adviser		
	Solicitor/Lawyer		
	Guardian		



How I live day to day – NOW

Think about how you are living your life now.

In this section, you're given the space to write down the detail for what is happening now:

- What you do in daily life, who helps you, what they do, and for how long
 - ◊ How could things be different for you
- The transport you use, who helps you and what it costs you
- What equipment and aids you use
- What consumable products you use
- What things make your day difficult

Then, you write down the detail for what you would like to make your life easier:

- Changes and supports you need across your **Life Domains**.



Tips at this point:

1. **Tell your NDIS planner everything.**

Do not sugar coat what is going on for you – share your worst day;

2. **Remember your carer/s**

Factor in up to 4 weeks leave for your carer. This could be scheduled weekly over the year. At these times you will require paid supports. Include this in your required paid supports;

3. **Ask for Support Coordination**

A Support Coordinator supports you with managing the changes and complexities of your HD support needs. They become your personal NDIS assistant, they will do all the leg work to find you service and support options and then you make the final decisions.









4. Your **HD Service key worker** is critical in helping you find the most appropriate **Support Coordination** contact.



My First Plan

My week looks like this....

SAMPLE ONLY

MONDAY						
	What I do	Who helps me?	Formal or informal supports (paid or unpaid)	What do they do for me?	For how long?	Is it working for me?  or 
Morning	Showering/ grooming	Myself	Unpaid		Myself—significantly longer	 managing ok 1 in 3 days only. I have trouble balancing & completing all tasks.
		Family	Unpaid	Ensure I remember to shower & groom, and check I've completed the task	Family—2 hours a couple of times per week	 Family need to take time out of work to support me
	Breakfast	Myself	Unpaid		Myself—significantly longer	 I forget to eat
		Family	Unpaid	Ensure I remember to eat	Family—2 hours a couple of times per week	 Family need to take time out of work to support me
	Take medication	Myself	Unpaid			 I get confused & forget to take my medication, 2 out of 3 days
		Family	Unpaid	Ensure I remember to take my medication	Family—2 hours a couple of times per week	 Family need to take time out of work to support me



My First Plan

My week looks like this....

SAMPLE ONLY

MONDAY						
	What I do	Who helps me?	Formal or informal supports (paid or unpaid)	What do they do for me?	For how long?	Is it working for me? 👍 or 👎
Afternoon	Domestic duties: clothes washing/ cleaning house	Myself	Unpaid		Myself— significant amount of time	👎 Have trouble planning & completing tasks
		Family	Unpaid	Wash clothes & house clean	Family—2 hours a couple of times per week	👎 Family need to take time out of work to support me
	Lunch	Myself	Unpaid		Myself— significant amount of time	👎 I get distracted & forget to eat 2 out of 3 days
		Family	Unpaid	Prepare meal & ensure I remember to eat	Family—2 hours a couple of times per week	👎 Family need to take time out of work to support me
	Grocery shopping / Banking	Myself	Unpaid		Myself— significant amount of time	👎 Have trouble planning & completing tasks
		Family	Unpaid	Wash clothes & house clean	Family—2 hours a couple of times per week	👎 Family need to take time out of work to support me

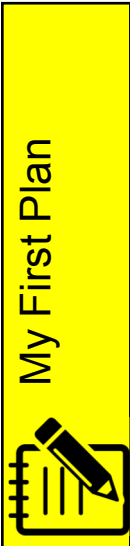


My First Plan



My week looks like this....

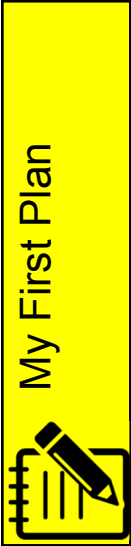
SAMPLE ONLY

MONDAY						
	What I do	Who helps me?	Formal or informal supports (paid or unpaid)	What do they do for me?	For how long?	Is it working for me? 👍 or 👎
Evening	Watching TV	Myself	Unpaid		I loose track of how long I've been watching the TV	👍 I would like to do an activity that interests me 👍 Relaxes me
	Dinner	Myself	Unpaid		Myself—significantly longer	👍 have trouble preparing my meal.
		Family	Unpaid	Ensure I remember to eat	Family—2 hours a couple of times per week	👍 Family need to take time out of work to support me
	Preparing for bed/ Grooming	Myself	Unpaid		Myself—significantly longer	👍 forget where my clothes are & have trouble dressing
		Family	Unpaid	Ensure my clothes are ready & help dress me	Family—2 hours a couple of times per week	👍 Takes away from my family time





My week looks like this.....

MONDAY						
	What I do	Who helps me?	Formal or informal supports (paid or unpaid)	What do they do for me?	For how long?	Is it working for me?  or 
Morning						
Afternoon						
Evening						



My First Plan



My week looks like this.....

TUESDAY						
	What I do	Who helps me?	Formal or informal supports (paid or unpaid)	What do they do for me?	For how long?	Is it working for me?  or 
Morning						
Afternoon						
Evening						



My First Plan



My week looks like this.....

WEDNESDAY						
	What I do	Who helps me?	Formal or informal supports (paid or unpaid)	What do they do for me?	For how long?	Is it working for me?  or 
Morning						
Afternoon						
Evening						



My First Plan



My week looks like this.....

THURSDAY						
	What I do	Who helps me?	Formal or informal supports (paid or unpaid)	What do they do for me?	For how long?	Is it working for me?  or 
Morning						
Afternoon						
Evening						



My First Plan



My week looks like this

FRIDAY						
	What I do	Who helps me?	Formal or informal supports (paid or unpaid)	What do they do for me?	For how long?	Is it working for me?  or 
Morning						
Afternoon						
Evening						



My First Plan



My week looks like this.....

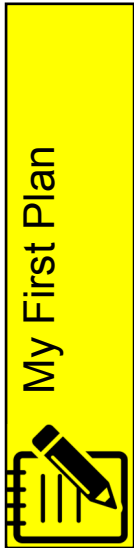
SATURDAY						
	What I do	Who helps me?	Formal or informal supports (paid or unpaid)	What do they do for me?	For how long?	Is it working for me?  or 
Morning						
Afternoon						
Evening						



My First Plan

My week looks like this.....

SUNDAY						
	What I do	Who helps me?	Formal or informal supports (paid or unpaid)	What do they do for me?	For how long?	Is it working for me?  or 
Morning						
Afternoon						
Evening						



My First Plan

My First Plan

My First Plan

How I get around—Transport Log

Day	Transport used	Distance travelled (kms)	Who supported you?	Out of pocket costs
Monday				
Tuesday				
Wednesday				
Thursday				
Friday				
Saturday				
Sunday				



The equipment I use

Write down the detail for the equipment you currently use or lease.

Equipment	Model	Supplier	Picture / photo
<input type="checkbox"/> Owned			
Purchase date:			
Purchase value: \$			
Warranty expiry date:			
<input type="checkbox"/> Leased / Hired			
Hire company:			
Hire start date: / /			
Hire Rate: \$			
Frequency:			
Hire renewal date: / /			
Daily upkeep			
Maintenance it requires (Quarterly/Annually)			

Repairs it needs – what's wrong with it?	
Does this equipment need to be replaced?	
<input type="checkbox"/> Through leasing company	
<input type="checkbox"/> New purchase	
Recommended by:	
Assessment date: / /	
Evidence dated: / /	
Summary of evidence:	



Tips at this point:


New equipment needs an assessment by an Occupational Therapist (OT) or Physiotherapist.

The Huntington Disease Clinic at Westmead Hospital can assist with recommending specific equipment suitable for your circumstances.

Contact (02) 8890 9960 or (02) 8890 6699 to access this HD specific service.



My First Plan

Equipment	Model	Supplier	Picture / photo
Care-Quip Toilet Safety Arms	B1013	Any	
<input type="checkbox"/> Owned			
Purchase date: 01/11/2016			
Purchase value: \$ 100.00			
Warranty expiry date: 31/10/2017			
<input type="checkbox"/> Leased / Hired			
Hire company:			
Hire start date: / /			
Hire Rate: \$			
Frequency:			
Hire renewal date: / /			
Daily upkeep			
<ul style="list-style-type: none"> Clean for hygiene using hospital grade disinfectant 			
<ul style="list-style-type: none"> Visually check all bolts, height adjustments points, 			
<ul style="list-style-type: none"> Inspect handles and anchor points for any loose or broken parts. 			
Maintenance it requires (Quarterly/Annually)			
<ul style="list-style-type: none"> Quarterly test standard frame functionality 			



My First Plan

Repairs it needs – what's wrong with it?

- *From daily upkeep, visual check*
- *From quarterly standard functionality test*

Does this equipment need to be replaced?

☐ Through my leasing company

☐ New purchase

Recommended by: *OT*

Assessment date: *01/08/2017*

Evidence dated: *01/08/2017*

Summary of evidence: *refer to OT assessment document*

Purchase value: \$ *130.00*

Warranty expiry: *12 months*



My First Plan

Maintenance Log

Date	Maintenance Description	What was done?	By Whom Name:	Phone:



My First Plan

Consumable Products

These are everyday use items you require to manage your personal needs. Many of them are disposable items or are consumed. These can include continence products, home enteral nutrition (HEN) products, low cost assistive products for eating and drinking, carer supplies and cleaning goods.

They are funded from the **Core budget** of a plan and have their own support category. The NDIS AT and Consumable Code Guide lists commonly used assistive technology (AT) and consumable supports.

Supplier code	Description	Number used	How often	Cost
<i>example</i>	<i>Sustagen Hospital Formula 800g</i>	<i>2</i>	<i>Monthly</i>	<i>\$50.00</i>
<i>example</i>	<i>Resource ThickenUp Clear 900g</i>	<i>1</i>	<i>Monthly</i>	<i>\$80.00</i>
<i>example</i>	<i>Adult Bibs</i>	<i>3</i>	<i>Daily</i>	<i>\$75.00</i>
<i>example</i>	<i>Long handled spoons</i>	<i>3</i>	<i>Daily</i>	<i>\$25.00</i>
<i>example</i>	<i>Gloup Medication Lubricant – 500ml</i>	<i>1</i>	<i>Monthly</i>	<i>\$40.00</i>
<i>example</i>	<i>Kylie Standard</i>	<i>3</i>	<i>Daily</i>	<i>\$125.00</i>
<i>example</i>	<i>Abri-Form Plus, Medium Pk14</i>	<i>2 packets</i>	<i>Weekly</i>	<i>\$50.00</i>

Record all the products you need for your care.



Consumable Products that I Need

[illegible]



My First Plan

What I find hard



Sometimes carers, family members, and friends are more aware of how your Huntington's Disease is affecting your daily life.

Ask them to help you to complete the next two pages. It is better for you if all difficulties are noted here so that you receive support that is appropriate for your own circumstances.

<input type="checkbox"/>	Fatigue – tiredness	<input type="checkbox"/>	Fatigue – muscular	<input type="checkbox"/>	Unable to get out of bed
<input type="checkbox"/>	Walking	<input type="checkbox"/>	Balance	<input type="checkbox"/>	Muscle Weakness
<input type="checkbox"/>	Thinking (concentration)	<input type="checkbox"/>	Memory recall	<input type="checkbox"/>	Planning
<input type="checkbox"/>	Involuntary Movement (jerks & twitches)	<input type="checkbox"/>	Coordination or clumsiness	<input type="checkbox"/>	Bladder & bowel control
<input type="checkbox"/>	Stiffness / Rigidity	<input type="checkbox"/>	Mood (depression/ anxiety/ or irritable/ frustrated)	<input type="checkbox"/>	Sleep - restless
<input type="checkbox"/>	Pain	<input type="checkbox"/>	Sensory changes (eg. pins & needles)	<input type="checkbox"/>	Heat/cold sensitivity
<input type="checkbox"/>	Being unwell	<input type="checkbox"/>	Swallowing problems	<input type="checkbox"/>	Low motivation
<input type="checkbox"/>	Slurred speech	<input type="checkbox"/>	Other behaviours		

These things make my day difficult



My First Plan

I find these tasks hard to do because of my Huntington's

<input type="checkbox"/>	Dressing	<input type="checkbox"/>	Showering	<input type="checkbox"/>	Grooming
<input type="checkbox"/>	Walking	<input type="checkbox"/>	Stairs /steps	<input type="checkbox"/>	Cooking
<input type="checkbox"/>	Washing the dishes	<input type="checkbox"/>	Clothes washing & hanging out	<input type="checkbox"/>	Cleaning
<input type="checkbox"/>	Shopping	<input type="checkbox"/>	Gardening	<input type="checkbox"/>	Driving
<input type="checkbox"/>	Planning/coordinating my week	<input type="checkbox"/>	Thinking on the spot	<input type="checkbox"/>	Making decisions
<input type="checkbox"/>	Accessing social activities	<input type="checkbox"/>	Maintaining relationships	<input type="checkbox"/>	Participating in family or community activities
<input type="checkbox"/>	Meeting new people	<input type="checkbox"/>	Participating in exercise	<input type="checkbox"/>	Accessing work, volunteering or education
<input type="checkbox"/>	Maintain my role as a partner (husband/ wife/ partner)	<input type="checkbox"/>	Intimacy (sex or bonding with others)	<input type="checkbox"/>	Maintain my role as a parent
<input type="checkbox"/>	Looking after my pet	<input type="checkbox"/>	Carrying items	<input type="checkbox"/>	Talking

☐ Others



My NDIS Participant Statement



Changes I want to make my life easier

What is working well or what could be improved?

Transfer the ‘*Is it working*’ information from ‘*My week looks like this....*’ from pages 24-30 into the appropriate **Life Domains** box below with some detail.



Add in other things like:

- changes in the amount of support your family, friends and community have
- the people you’d like to see more and less of
- your parenting or child rearing demands
- changes you’d like to make in your work and/or education environments
- changes you’d like to make in your home
- changes you’d like to make in your social life and/or community participation

 What’s working?	 What’s not working?
Daily Living	
Home	





My First Plan

 What's working?	 What's not working?
Health and Wellbeing	
Parenting and Child Care	
Social and Community Participation	
Relationships	



My First Plan

 What's working?	 What's not working?
Choice and control You're in charge and you choose how, when, where and by whom your supports are to be provided.	
Education	
Work	



My First Plan

Supports I want to make my life easier

Now it's time to summarise the information you've write down from the exercises in the previous pages. This will make it easier for you and your **NDIS planner** to identify the **reasonable and necessary supports** you need immediately.

- Tick the things that you currently need support with and its detail, *from pages 24—39*
- Include any gaps you've noticed with your current supports, *from pages 40—44*
- Add in what you think you will need in the next 12 months and its detail



Tips at this point:

Ask your support team to help you with predicting for the next 12 months.

Additional assessments or evidence may need to be provided to the **NDIS planner** as supporting documentation. These may include: assessments from Allied Health: Speech

I need support with / to...		NDIS Category	Hours needed	How often?
Assistance with my daily living	Personal care			
	<input type="checkbox"/> showering	Core		
	<input type="checkbox"/> cleaning teeth	Core		
	<input type="checkbox"/> toileting	Core		
	<input type="checkbox"/> grooming	Core		
	<input type="checkbox"/> dressing	Core		
	<input type="checkbox"/> organising myself	Core		
	<input type="checkbox"/> overnight care	Core		
	Meal times			
	<input type="checkbox"/> cooking	Core		
	<input type="checkbox"/> eating	Core		
	<input type="checkbox"/> drinking	Core		
	<input type="checkbox"/> tube feeding	Core		
	Communication and organisation			
	<input type="checkbox"/> interpreting or understanding information	Core		



My First Plan

	I need support with / to...	NDIS Category	Hours needed	How often?
Assistance with my daily living Continued	<input type="checkbox"/> learning and practising new ways of communicating	Capacity Building		
	<input type="checkbox"/> problem solving and planning	Capacity Building		
	<input type="checkbox"/> organising appointments and finances	Core		
	<input type="checkbox"/> operating computers, phones &/or tablets	Capacity Building		
	<input type="checkbox"/> other			
	Housework and maintenance			
	<input type="checkbox"/> cleaning	Core		
	<input type="checkbox"/> laundry	Core		
	<input type="checkbox"/> lawn and garden maintenance	Core		
	<input type="checkbox"/> handyman jobs	Core		
	Home – odd jobs			
	<input type="checkbox"/> window cleaning	Core		
	<input type="checkbox"/> tree maintenance	Core		
	<input type="checkbox"/> spring cleaning	Core		
	<input type="checkbox"/> clothes sorting	Core		
	<input type="checkbox"/> decluttering	Core		
	Shopping			
	<input type="checkbox"/> groceries	Core		
	<input type="checkbox"/> clothes or household goods	Core		
	Driving			
	<input type="checkbox"/> drive my own car	Core		
	<input type="checkbox"/> modifications to drive my own car	Capital		
	Parenting			
	<input type="checkbox"/> learning and practising new ways of parenting/catering for my child/ren's daily needs (ADL)	Capacity Building		
	<input type="checkbox"/> learning and practising new ways of parenting/caring for my child/ren's development	Capacity Building		
	<input type="checkbox"/> Bonding, communication and behavioural management	Capacity Building		
	<input type="checkbox"/> Childcare (child minding)	Core		
	Support to keep my informal supports			
	<input type="checkbox"/> short-term accommodation	Core		
	<input type="checkbox"/> carer leave	Core		
<input type="checkbox"/> holiday or time away from family				



My First Plan

I need support with / to...	NDIS Category	Hours needed	How often?
Occasional Care			
<input type="checkbox"/> personal care appointments—hair, beauty	Core		
<input type="checkbox"/> holidays	Core		
<input type="checkbox"/> sickness of self or informal supports	Core		
<input type="checkbox"/> emergencies – personal alarm service	Core		
<input type="checkbox"/> equipment hire when holidaying	Capital		
Specialist accommodation			
<input type="checkbox"/> supported accommodation	Core		
<input type="checkbox"/> shared housing with support	Core		

Support description	NDIS Category	Details
Home modifications for safety		
<input type="checkbox"/> bathroom modifications	Capital	
<input type="checkbox"/> kitchen modifications	Capital	
<input type="checkbox"/> toilet modifications	Capital	
<input type="checkbox"/> outdoor modifications	Capital	
<input type="checkbox"/> ramp/s	Capital	
<input type="checkbox"/> railing/s	Capital	
<input type="checkbox"/> electronic door opener install & repairs	Capital	
<input type="checkbox"/> environment adaption to care for children	Capital	
<input type="checkbox"/> other	Capital	
Assistive technology		
<input type="checkbox"/> communication aids	Capital	
<input type="checkbox"/> eating and drinking aids	Capital	
<input type="checkbox"/> showering / toileting aids	Capital	
<input type="checkbox"/> grooming aids	Capital	
<input type="checkbox"/> special equipment to care for my children	Capital	
<input type="checkbox"/> seating cushions	Capital	
<input type="checkbox"/> walking frame/walking cane	Capital	
<input type="checkbox"/> wheelchair/scooter	Capital	
<input type="checkbox"/> lift chair	Capital	
<input type="checkbox"/> pressure mattress	Capital	
<input type="checkbox"/> NOVACor bed	Capital	



My First Plan

Support description	NDIS Category	Details
Assistance with my daily living Continued	<input type="checkbox"/> bedtime comfort products - cushions	Capital
	<input type="checkbox"/> restraint systems (including repairs)	Capital
	<input type="checkbox"/> CPAP / BIPAP machine	Capital
	<input type="checkbox"/> hoist / sling	Capital
	<input type="checkbox"/> enteral nutrition pump	Capital
	<input type="checkbox"/> exercise / sporting equipment	Capital
	<input type="checkbox"/> personal alarm system	Capital eg, Vitacall
	<input type="checkbox"/> environmental control unit	Capital eg, Air Conditioner
	<input type="checkbox"/> equipment adaptations - weights / visuals	Capital
	<input type="checkbox"/> swivel seat	Capital
	<input type="checkbox"/> Wii / xBox with Kinect	Capital
	<input type="checkbox"/> other	
	<input type="checkbox"/> other	
	Consumables	
	<input type="checkbox"/> carer supplies	Core
	<input type="checkbox"/> eating and drinking equipment	Core
	<input type="checkbox"/> nutrition supplements	Core eg, Sustagen, Ensure Plus
	<input type="checkbox"/> grooming equipment	Core
	<input type="checkbox"/> continence products	Core
	<input type="checkbox"/> bed pads	Core
	<input type="checkbox"/> CPAP / BIPAP supplies	Core
	<input type="checkbox"/> enteral nutrition supplies	Core
	<input type="checkbox"/> other	
	<input type="checkbox"/> other	

I need support with or assistance from...	NDIS Category	Hours needed	How often?
My Education and Work	Education		
	<input type="checkbox"/> a teacher's aid / support worker	Core	
	<input type="checkbox"/> researching educational opportunities	Capacity Building	
	<input type="checkbox"/> developing strategies, goals and educational plan with teachers	Core	
	<input type="checkbox"/> monitoring and reviewing goals and educational plan	Core	
	<input type="checkbox"/> transport to & from educational setting	Core	
	<input type="checkbox"/> other		

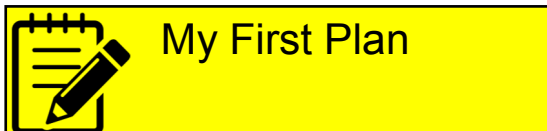


My First Plan

I need support with or assistance from...		NDIS Category	Hours needed	How often?
My Education & Work	Work			
	<input type="checkbox"/> career guidance	Capacity Building		
	<input type="checkbox"/> developing strategies, goals and work plan with employer	Core		
	<input type="checkbox"/> monitoring and reviewing goals and work plan	Core		
	<input type="checkbox"/> transport to & from work setting	Core		
	<input type="checkbox"/> other			

I need support with ...		NDIS Category	Hours needed	How often?
My Health and Wellbeing	<input type="checkbox"/> maintaining my fitness and safety i.e. personal trainer / exercise physiologist / gym attendance exercise classes	Core		
	<input type="checkbox"/> attending medical, allied health and mental health appointments and assessments	Core		
	<input type="checkbox"/> developing strategies, goals and making decisions about treatments and therapies	Core		
	<input type="checkbox"/> monitoring and reviewing goals and treatment/therapy plan	Core		
	<input type="checkbox"/> transport to & from medical, allied health and mental health appointments and assessments	Core		
	<input type="checkbox"/> managing medication	Core		
	<input type="checkbox"/> implementing treatment and therapies in the home or community	Core		
	<input type="checkbox"/> operating prescribed equipment	Core		
	<input type="checkbox"/> other			

I need support with ...		NDIS Category	Who can help me?	How often?
My Participation	Social & community			
	<input type="checkbox"/> researching opportunities to socialise	Support Coordination		
	<input type="checkbox"/> developing strategies, goals and making decisions about my participation plan	Support Coordination		
	<input type="checkbox"/> booking, monitoring and reviewing my participation plan goals	Support Coordination		
	<input type="checkbox"/> transport to & from social activities	Support Coordination		
	<input type="checkbox"/> paying the invoices for my social activities	Plan Management		



My desires/goals

The final aim of the **NDIS planning meeting** is to begin your thinking around any goals you want to achieve.

A goal is something you're wanting to do in or with your life.

Every person's goals are unique to them and their life circumstances.

For example:

- I want to increase my social outings to the football to twice a month
- I need a ramp into my backyard to reduce my falls and because I want to play with my dog
- I want to meet people with HD and socialise with them
- I need someone to take me to my appointments
- I want some technology to help people understand what I am trying to communicate to them

Need or Goal (I want / need to (verb) ..)	How I want this to happen	Who can help me?	Priority
Daily Living			



My First Plan

Need or Goal (I want / need to (verb) ..)	How I want this to happen	Who can help me?	Priority
Home			
Health and Wellbeing			
Social and Community Participation			



My First Plan

Need or Goal (I want / need to (verb) ..)	How I want this to happen	Who can help me?	Priority
Choice and control You're in charge and you choose how, when, where and by whom your supports are to be provided.			
Education			
Work			



Carer statement

A carer can be the most important person in your life. It is vital to your **NDIS planning** that they are allowed to submit a Carer Statement to your **NDIS planner** as supporting documentation for your **NDIS plan**.

This statement provides an opportunity for your carer/s to reflect on their ability to sustain their role as your carer and advise how they may see it changing.

Carers should think about how life was before HD and note how your time and finances have been impacted because of the effect of HD.

We have chosen not to rewrite this section as there are great resources already available for use. We recommend:

- Carer statement considerations by Carers Australia
Found at: <http://www.carersaustralia.com.au/ndis-and-carers/support-for-families-and-carers/>
- NDIS Carer Statement by the Mental Health Carers NSW Inc.
Found at: <http://www.arafmi.org/wp-content/uploads/2017/05/NDIS-Carer-Statement-Template-3.pdf>
- Carers Checklist by Carers Australia
Found at: <http://www.carersaustralia.com.au/storage/carer-checklist-new-writable-sept-2016.pdf>



Managing my NDIS plan

The following categories require your careful consideration as they are opportunities for you and your support team to make your NDIS journey easier. Managing your **NDIS plan** is similar to running a small business solely for you. There is professional assistance available to find and sign up providers, manage your bookings and then pay their bills on time.

Support Coordination (the bookings)

Support Coordination is essential for HD **NDIS participants** (you). People with HD are considered to have high support needs within the NDIS. This is due to the complexity of the supports and services required to care for you in your physical, cognitive and behavioural degeneration.

The Support Coordinator becomes a crucial part of your support team. They are your personal assistant for the **NDIS**; they should work collaboratively with your **HD Service key worker** and your **carer** or guardian.

Support coordination enables you to:

- get value for money from your supports and services
- have your choices heard and fulfils your decisions
- put your NDIS plan into action
- manage what you like directly
- explore and connect with community and alternative support options
- better coordinate multiple supports and services
- strengthen the capacity of your informal support team
- access and use the NDIS Participant Portal myplace



My First Plan

Plan management (the money)

There are 4 ways to manage your NDIS funds or budget.

You choose one or a combination of the options below.

1. **Self-Managed** – you draw from your NDIS funds to directly pay people or organisations who are providing you the support.
 - a. **You are responsible** for paying the providers at the agreed time; managing your costs; keeping accurate accounting records for 5 years keeping the NDIA advised of the funds spent.
 - b. You can directly employ your own staff or pay someone else to employ them on your behalf.
2. **Plan Managed** – your NDIS plan employs a registered **plan management** provider to pay the bills on your behalf.
 - a. The **plan manager** is responsible for paying the providers at the agreed time; managing your costs; keeping accurate accounting records for 5 years; and keeping the NDIA advised of the funds spent.
 - b. The plan manager can teach you how you can manage your plan.

NDIA Managed – you ask the **NDIA** to manage your funds.

Only NDIS registered providers can be chosen with this option.

Plan nominee – you **nominate a person** from your support team to pay the bills on your behalf.

Your nominee is responsible for paying the providers at the agreed time; managing your costs; keeping accurate accounting records for 5 years; and keeping the NDIA advised of the funds spent.



My First Plan

Appointing a Nominee

A nominee is responsible for ensuring your wishes are honoured and making decisions that are of benefit to your personal and social wellbeing. If a guardianship arrangement exists, it is presumed that the guardian will be appointed the nominee.

There are 2 types of nominees:

A **correspondence nominee** can undertake all activities for you except for the preparation and review of your **NDIS plan** and managing your **NDIS funds**.

A **plan nominee** can undertake all activities that you would undertake under the scheme except those that you outline as part of their appointment.

When appointing a **nominee**, you then give consent for the **NDIA** to collate and share information about you with the person you have appointed.



How I want to manage my NDIS plan

Think about your abilities and the abilities of those in your support team.

Ask yourself the following questions when you respond to the statements in the boxes below:

- How much help will you need to put your NDIS plan into action?
- Who in your support team might be able to help you with your NDIS plan?

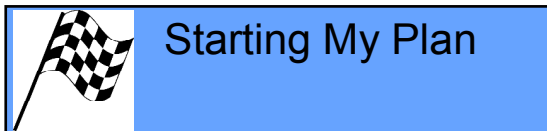
As at date: / /

I need support with...		NDIS Category
<input type="checkbox"/>	researching possible service providers to deliver the supports approved in my NDIS plan	Support Coordination
	contacting, meeting and interviewing possible service providers regarding delivering the supports approved in my NDIS plan	Support Coordination
	deciding which service providers can deliver the supports approved in my NDIS plan	Support Coordination
	making an agreement for services or supports to deliver the supports approved in my NDIS plan	Support Coordination
	paying service providers for supports and services delivered to me through my NDIS plan	Plan Management

Results:

I believe I need assistance with my NDIS plan in the following ways:

- ☐ *Support Coordination*
- ☐ *Plan Management*



My NDIS Plan Summary

My NDIS Participant No: _____

My NDIS Nominee is: _____ Phone: _____
 Email: _____

My NDIS Planner is: _____ Phone: _____
 Email: _____

My NDIS Support Coordinator is: _____ Phone: _____
 Email: _____

My Plan Manager is: _____ Phone: _____
 Email: _____

My LAC office location: _____ Phone: _____
 Email: _____

Support description	Reference No:	How will the supports be paid	Can only be used from	Purpose of the support	Budget
Total NDIS Plan amount					

Review dates		
Plan No.	Requested	Actioned
	/ /	/ /



Notes	To Do List

Appendix

What does that word mean?

Throughout this workbook there are words that have been highlighted in **bold**. These are NDIS words that are handy for you to understand the meaning of.

Find the word below and let us know if it still is not clear.

Carer - a family member or friend who provides primary support caring for you.

Budget - An **NDIS Plan** has three support budgets (Core, Capital and Capacity Building) and you will receive **reasonable and necessary** funding under the relevant budget depending on your support needs.

Formal supports - these are people you pay to provide you with help.

Informal supports – these are people who help you without receiving payment. This might include: friends, family, neighbours, people from your work, school or church, and/or community groups (support group, exercise, day program).

Key worker – a professional person who works closely with you in regard to your well-being in society such as a member of the HD Service team or a Social worker.

LAC – Local Area Coordinator – organisations such as St Vincent De Paul and Uniting have been commissioned by the NDIA to transition people, in their local area, onto the NDIS. This is done through their NDIS planners, community workshops and basic coordination (support connection).

Life Domains – are areas of life where you can set NDIS goals. Your NDIS goals align to one of these areas: daily living, your home, your health and wellbeing, your learning/education, your work, your social activity, your relationships, and choice and control.

NDIA – the National Disability Insurance Agency, the governing organisation (including workers) accountable for ensuring the NDIS is running smoothly for NDIS participants.

NDIS – the National Disability Insurance Scheme.

NDIS pathway – the NDIS process a participant follows.

NDIS planner - a worker from the NDIA or a LAC who helps an NDIS participant put together your NDIS plans. Use the information in this workbook to help the planner understand what your days look like and what goals you'd like to reach.

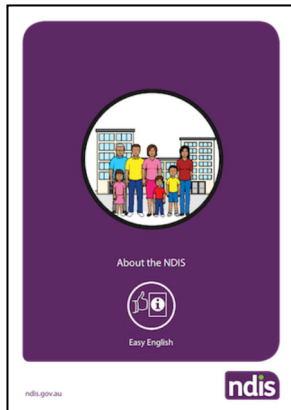
NDIS plan – a report tailored to your specific needs of a participant. It's created from the information given in an NDIS planning meeting with an NDIS planner.

NDIS planning meeting – a time set aside with an NDIS planner, an NDIS participant and their advocates, to understand and accurately record information about an NDIS participant for the purpose of producing an NDIS plan.

Nominee – a person who is appointed to act and make decisions for a participant who does not have a parent or guardian.

Participant (you) – a person who has eligibility criteria is an Australian citizen, is 65 years and under, and has a lifelong disability.

NDIS Fact Sheets and Videos we think you need to be aware of

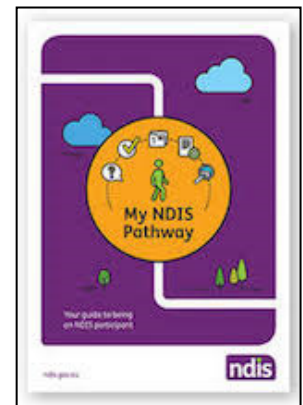


About the NDIS

<https://www.ndis.gov.au/html/sites/default/files/documents/About-us/About-theNDIS.pdf>

My NDIS Pathway

<https://ndis.gov.au/html/sites/default/files/My-NDIS%20-Pathway.pdf>



Developing your first plan

<https://ndis.gov.au/medias/documents/hee/ha0/8798779113502/Fact-Sheet-Developing-your>

Supporting families and carers

<https://www.ndis.gov.au/html/sites/default/files/Supporting-families-carers.pdf>



Getting ready for your planning conversation

<https://www.ndis.gov.au/medias/documents/h68/h80/8798779670558/Checklist-Getting-ready-for-your-planning-conversation-21.10.16-accessible.pdf>

