

Carer Checklist

to prepare for the National Disability Insurance Scheme assessment & planning meetings

Purpose of this Checklist

This checklist is designed to assist carers to describe the support they provide to contribute to the National Disability Insurance Scheme (NDIS*) planning process. It is not a compulsory part of the NDIS planning process and you do not have to complete it. It may be of use to you in the preparing for your participation in planning sessions or in talking to the NDIS about your role.

**Words and acronyms in bold are explained at the end of this document.*

Background

Under the NDIS people with disability will be assessed for their eligibility to receive an individual funded package of support. If they are deemed eligible, each participant will have a meeting with the National Disability Insurance Agency (NDIA) to develop their individual plan. This plan outlines the supports that will be funded by the NDIS and is tailored to their goals, personal circumstances and disability support needs.

Who is this checklist for?

This checklist is for people who provide unpaid care and support to a family member or friend with a **disability** who is a **participant** in the **NDIS** or who is eligible to be a **participant**.

How to use this checklist

Filling out the checklist will assist carers to think about and describe the supports they provide to a person with a disability.

It is common for carers to feel confused, nervous and maybe even a bit overwhelmed by how to help the person they care for to access and prepare for the **NDIS**. This is normal, and it is important to remember that the **NDIA** staff are there to help you and the person you care for to achieve a positive outcome.

How carers are involved in **NDIS** assessment, planning and review processes will vary according to individual **participants'** circumstances. For example, carers might go along to the planning meeting with the **participant**, be listed in the **participant's** plan as an informal support and/or help the **participant** to access funded services and supports. It is important for the **NDIA** to understand what your caring role involves so that the support package allocated to the person you care for meets their needs and supports your ongoing caring role.

Important information may include what you do as a carer, how often you do these tasks and how caring is affecting you and other family members. You will also need to tell the **NDIA** if you want to keep providing the same level of care, or if you need extra help and support to keep providing care.

The questions on the following pages are a prompt to help you think about what you will need to tell the **NDIA**. For those who care for someone with an episodic (on and off) condition or disability, you may need to explain how your caring role changes when the care recipient is relatively 'well' versus when they are unwell.

Please remember, this is not a complete list and there may be other issues you need to discuss with the NDIA which are not mentioned here. A useful question to ask yourself may be; "If I was away or unable to care for a week, what would I need to tell the person who took over my caring role?"

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The caring context

Think about the context of your caring role and how this affects you.

Living arrangements

Does the person you care for live with you? (either permanently or occasionally) yes / no

Would you or the person you care for prefer to change this arrangement? yes / no

If the person you care for lives elsewhere, are you responsible for ensuring they have affordable, safe, secure and suitable accommodation? yes / no

Are you financially responsible for accommodation? yes / no

Are you financially responsible for maintaining the accommodation/property? yes / no

Does it take you a long time to travel to where the person you care for lives? yes / no

If yes, how long and by what transport?

Can the current arrangements continue in the short to medium term? yes / no

If no, why?

Other comments:

Additional caring responsibilities

- Do you care for more than one person with a disability or illness?
- Do you care for other family members who are unable to fully care for themselves? (e.g. children - either your own or the children of the person you care for).
- Do you think your family circumstances may change in the near future and you may take on additional caring duties (e.g. for ageing parents)? If yes, will this affect the current level of care you provide?

Comments:

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Other supports

- Does anyone else also undertake caring responsibilities for the person? How do they help?

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Culture & religion

- Are you able to access culturally appropriate services and supports?
For example services that translate into your preferred language and where you can express your religious practices or aspects of your culture without judgement.

Comments:

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Mobility

Do you assist the person you care for with mobility?

For example:

- Ensuring the person you care for does not fall
- Assistance with moving around the house
- Helping the person you care for to hold and manage objects
- Helping the person you care for to sit up
- Turning the person you care for over during the night

Tasks	Time spent	How often

Meal preparation, eating & drinking

Do you assist the person you care for with meal preparation, eating & drinking?

For example:

- Preparing food
- Spoon feeding ensuring the person you care for doesn't choke while eating
- Keeping check on unhealthy eating habits
- Assistance with tube feeding

Tasks	Time spent	How often

Safety

Do you assist the person you care for to be safe?

For example:

- Dealing with problematic alcohol or drug use
- Ensuring the environment is safe from trip hazards
- Ensuring the person you care for does not wander off
- Checking water temperature
- Preventing the person you care for from hurting themselves or others

Tasks	Time spent	How often

Domestic life

Do you assist the person you care for with domestic activities?

For example:

- Helping the person you care for with managing finances
- Washing their clothes
- Support and encouragement in cleaning their house
- Helping to care for their pets
- Paying rent and bills
- Helping the person you care for shop for groceries
- Encouraging and helping the person you care for to get up in the morning and to keep healthy sleeping patterns

Tasks	Time spent	How often

Providing emotional support & behaviour management

Do you assist the person you care for with behaviour management?

For example:

- Helping the person you care for manage symptoms of mental illness (such as anxiety or hearing voices)
- Reassuring and calming the person you care for if they're distressed
- Providing support through events the person is worried or concerned about
- Assisting with managing the person's environment to avoid triggers for stress
- Supported decision making
- Assisting and providing suggestions on positive ways of responding to challenges and stresses
- Managing behaviours
- Motivating and assisting to reframe thoughts in a positive manner
- Encouraging or providing assistance with planning and problem solving

Tasks	Time spent	How often

Health & treatment

Do you assist the person you care for with their health and treatment?

For example:

- Researching or discussing treatment or therapy options with participants
- Arranging or giving medications and/or managing wound dressings
- Operating medical equipment
- Planning for and providing transport to medical appointments
- Reminding, encouraging and supporting the person you care for to take medication or to follow a prescribed treatment

Tasks	Time spent	How often

Communication & social participation

Do you assist the person you care for with communication & social participation?

For example:

- Helping the person you care for communicate their needs to you or others
- Providing and helping to organise social activities with others
- Reducing/calming anxiety and fear about leaving the house and/or interacting with others
- Assistance with interpreting or understanding information
- Providing transport for social activities and/or attending with the person you care for
- Encouraging and supporting the person you care for to interact and engage with other people

Tasks	Time spent	How often

Advocacy & representation

Where necessary you may need to be an **advocate** and represent the person you care for in their personal matters.

Do you assist the person you care for with advocacy & representation?

For example:

- Assisting the person you care for to access appropriate services and supports
- Organising appointments
- Helping the person you care for to stand up for themselves and negotiate their personal affairs such as managing their finances and maintaining stable accommodation

Tasks	Time spent	How often

Coordination of services & supports

Do you assist the person you care for to coordinate services & supports?

For example:

- Arranging support services
- Filling in application and assessment forms
- Researching support options
- Phone calls to providers and government departments to arrange income support or access to services

Tasks	Time spent	How often

Employment, education, training

Do you assist the person you care for with employment, education and/or training?
For example:

- Transporting the person you care for to and from work or education/training
- Assisting the person you care for to understand and complete tasks
- Reminding the person you care for of starting times or projects in need of completion

Tasks	Time spent	How often

Total time spent on all caring activities

Per day

Per week

The impact of caring on you

There is no separate carers' needs assessment in the NDIS and no support plan for carers. However, it is still important that the planner understands the impact of your caring role. The following may help you to think about and describe this impact.

Physical & mental health

- How are you physically and emotionally?
- Do you have any medical conditions which currently (or may in the near future) affect your caring role?
- Does your caring role affect your physical or mental health? For instance, do you experience depression or anxiety?
- Have you sustained any injuries due to caring?
- Does the behaviour of the person you care for ever put you or other family members at risk of harm or injury or impact negatively on your physical and or emotional health and wellbeing?

Comments:

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Financial

Do you have any added financial burdens as a result of your caring responsibilities?
For example, do you pay or contribute to the costs of:

- Services or supports
- Transport to appointments
- Additional child-care costs (for other dependent children whilst attending to the person you care for, or for their children)
- Medication or treatment
- Accommodation costs
- Legal bills

Comments:

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Time

- Does your caring role regularly prevent you from looking after yourself, taking time out or meeting other family responsibilities or activities?
- Does it prevent you from undertaking domestic tasks such as shopping or cleaning, or attending your own medical appointments?
- Does it isolate you from other family and friends or social activities?

Comments:

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Employment & education

- Are you currently in full or part-time work, education or training?
- Have you had to reduce the time you put into any of these either partly or completely due to your caring role?
- Would you like to undertake work, education or training but are unable to due to your caring role?

Comments:

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Services & support

Think about any current services and supports you may receive and what other assistance may help you to continue in your caring role.

Continuing care

- Can your current caring arrangements continue over time without more services or support?
- Do you think you can continue to provide the same level and type of care?

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Accessing services & supports

- Have you been able to access services and supports you need?
- Do you need to travel long distances to get certain services or supports?
- Do you have private transport?
- Are you able to use public transport or are you required to use taxis?
- Are you on any waiting lists to access support?
- Have you had any issues with the quality of services and support you receive?

Comments:

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Caring needs

What would help you with caring?

For example:

- Professional assistance with accessing, managing and coordinating services for the person you care for (case management)
- Information on financial support which may be available
- How to access **early intervention**
- More information about the condition of the person you care for and treatment options
- Education/training about how to respond in a positive and helpful way in distressing or challenging situations
- Assistance in looking after your own health and wellbeing
- Assistance from professional cleaners
- Access to counselling or support groups

Would access to certain services and supports help you to continue providing care?

For example, taking a short break from caring (respite) while the person you care for is being looked after by someone else (either in the home or elsewhere). Respite could be for a short time, a holiday or on a regular basis.

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Emergencies/alternative arrangements

- Do you have a plan for when you are unable to provide care? (Either in response to a short-term crisis or for the longer-term).
- Do you need any information or assistance to make such a plan?
- Do you have an Emergency Care Plan or advance directive, which the NDIA should know about?
- Is the plan of the person you care for flexible enough to respond to changing circumstances or support needs?

Comments:

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Key terms

Advance directive	An advance directive is a document prepared by the person with disability to be read and used in case of a crisis. Typically advance directives contain special information outlining a person’s unique circumstance, personal preferences regarding treatment choices and information about practical life management arrangements. An advance directive outlines the steps that must be taken to provide optimal support and care for a person during a time of crisis in order to limit or prevent the damage from that crisis.
Advocate	A person who aims to increase a person’s control over goods, services and quality of life, to develop a sense of empowerment and of being valued as an individual. Advocates support the needs, wishes and rights, including protection of confidentiality, of that person. Advocates may ask for change or challenge what is unfair, unjust and wrong.
Carer	Someone who provides unpaid care and support to a family member or friend with a disability, mental illness, chronic condition, terminal illness, drug or alcohol problem, or those who are frail aged. A carer may or may not live with the person they support, and may not be identified by the individual to be their carer.
Early Intervention	Providing supports to a person with disability early on to reduce the amount of support they may need in the future.
Emergency care plan	An Emergency Care Plan is a document that provides instructions and guidance to allow someone else to step in and provide the care which you would normally provide. An Emergency Care Plan can give you reassurance that if anything should happen to you, the person you care for will still receive the support they need.
Individual funded package	Eligible NDIS participants receive an individualised plan which outlines the supports which will be funded by the NDIS . This is called an individual funded package.
NDIA	National Disability Insurance Agency. The NDIA is in charge of running the NDIS .
NDIS	National Disability Insurance Scheme.
Participant	An individual who is an eligible participant in the National Disability Insurance Scheme.
Respite	A short break from the caring role that may include replacement care in the home, activities outside the home for the person receiving care, or replacement care in a residential facility.