



# Checklist for people affected by multiple sclerosis

## - conversation with NDIA

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### THE FOLLOWING CHECKLIST IS TO HELP YOU TO:

- prepare your ideas and thoughts about your support network,
- determine what is important in your life,
- identify how individual funded supports may assist you
- understand the steps to accessing NDIS and
- **be ready for your conversation with NDIA**

The checklist is not an exhaustive list, but a tool to help you think about how and what support will assist you to be active in the way you live your life. What you want to achieve (goals) and what barriers may exist in achieving these goals, *i.e. my balance and strength makes it difficult to do the shopping alone, I am so tired with work I struggle to maintain connections with my family.*

**If you would like an MS representative to work through this checklist, and /or you would like to talk about the NDIS please call MS Connect on 1800 042 138.**

The criteria for eligibility for NDIS considers a person's age, impairment/s, whether the impairment/s is permanent or likely to be permanent

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### THINGS I NEED TO THINK ABOUT:

#### 1. INFORMAL SUPPORTS IN YOUR NETWORK

**Who provides you with the most informal support? You can pick more than one:**

- |  |  |
|--|--|
| <input type="checkbox"/> My partner or spouse  | <input type="checkbox"/> My child(ren) |
| <input type="checkbox"/> A close family member | <input type="checkbox"/> A friend      |
| <input type="checkbox"/> A neighbour           | <input type="checkbox"/> A volunteer   |
| <input type="checkbox"/> A grandchild          | <input type="checkbox"/> A parent      |

Other \_\_\_\_\_

**Of these people above, who would you identify as your primary carer (someone who provides most of your care and support)?** \_\_\_\_\_

**Does your primary carer:**

- |   |  |
|---|--|
| <input type="checkbox"/> Reside in the same home? | <input type="checkbox"/> Live elsewhere? |
|---|--|

**2. COMMUNITY PARTICIPATION:**

- Library services
- Education (incl. TAFE /courses)
- Gym / fitness programs
- Social support/ peer groups
- Museums and galleries
- Recreational activities
- Emotional support / counselling
- Spiritual groups and services
- Other: \_\_\_\_\_
- Child Care / Before & After School Care
- Volunteering, employment opportunities
- Interest groups (craft/ art/ collectors)
- Meeting with friends/ family
- Community programs (Men Shed)
- Health and wellbeing (massage)
- Music, drama events, movies
- Shopping and retail

**3. WHAT IS IMPORTANT TO ME TO MAINTAIN? WHAT IS/ARE MY GOAL(S)?**

- To maintain my living arrangements
- To maintain family, relationships and activities
- Access to the community
- Increased mobility
- Increased independence
- To maintain my employment
- To maintain volunteering
- My health and wellbeing (e.g. maintain community exercise program, access to appointments)
- Others: \_\_\_\_\_

Comments:

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**4. WHAT ARE THE SYMPTOMS THAT MAKE ACHIEVING MY GOALS DIFFICULT?**

- Fatigue
- Walking
- Thinking
- Tremor
- Coordination
- Sensory changes (e.g. pins & needles )
- Others \_\_\_\_\_
- Heat/cold sensitivity
- Memory
- Bladder
- Balance
- Mood (depression)
- Pain
- Planning
- Muscle Weakness
- Spasticity
- Sleep

Comments:

**5. WHAT ARE THE TASKS THAT ARE HARD TO DO BECAUSE OF MY MS SYMPTOMS?**

- |   |  |                                    |
|---|--|------------------------------------|
| <input type="checkbox"/> Walking                        | <input type="checkbox"/> Stairs /steps   | <input type="checkbox"/> Cooking   |
| <input type="checkbox"/> Washing the dishes             | <input type="checkbox"/> Hanging clothes on line                               | <input type="checkbox"/> Cleaning  |
| <input type="checkbox"/> Carrying items                 | <input type="checkbox"/> Participating in family activities                    | <input type="checkbox"/> Gardening |
| <input type="checkbox"/> Community access               | <input type="checkbox"/> Clearly thinking on the hop                           | <input type="checkbox"/> Shopping  |
| <input type="checkbox"/> Accessing social activities    | <input type="checkbox"/> Maintaining relationships                             | <input type="checkbox"/> Driving   |
| <input type="checkbox"/> Personal care                  | <input type="checkbox"/> Participating in Exercise                             |                                    |
| <input type="checkbox"/> Public transport               | <input type="checkbox"/> Access to education / training                        |                                    |
| <input type="checkbox"/> Accessing work or volunteering | <input type="checkbox"/> Maintain my role as a partner (husband/wife/de facto) |                                    |
| <input type="checkbox"/> Planning/coordinating my week  | <input type="checkbox"/> Maintain my role as a parent                          |                                    |
| <input type="checkbox"/> Others _____                   |  |                                    |

Comments:

**6. WHAT ARE THE BARRIERS TO ACTIVITIES AND TASKS?**

- |   |  |                                       |
|---|--|---------------------------------------|
| <input type="checkbox"/> Finance          | <input type="checkbox"/> Transport         | <input type="checkbox"/> House design |
| <input type="checkbox"/> Motivation/ mood | <input type="checkbox"/> Lack of equipment |                                       |
| <input type="checkbox"/> Other: _____     |  |                                       |

**7. HAVING THOUGHT ABOUT THE TASKS THAT ARE HARD FOR YOU TO DO, AND THE BARRIERS YOU FACE, WHAT THINGS WOULD SUPPORT YOU TO ACHIEVE YOUR GOALS?**

**Improved Daily Living**

- Equipment to increase my independence
  - Scooter
  - Chair
  - Walker
  - Hoist
  - Bed
- Respite to give me and my partner a break
- Assistance with person care
- Support with domestic tasks both in the home and garden (i.e. putting garbage bins out)
- Education and support in managing continence
- Assistive technology & communication tools (screen reader, magnifier, and emergency call system)

**Improved Environment**

- Kitchen modifications
- Air conditioning/cooling products to assist me with my fatigue and sleep
- Bathroom modifications

- Assistive technology (environmental controls)
- Equipment (rails, hoist, kitchen aids, shower/commode chair)
- Ramps
- Other

### **Improved Health and Wellbeing**

- Physiotherapy assessment to provide an exercise program
- Occupational Therapy (OT) assessment to provide help with a fatigue management plan
- OT assessment to provide recommendations about modifying my home (i.e. make moving about my home easier)
- Having someone to talk through future lifestyle planning and adjustment to change
- Individualised information/education and support for me and my family
- Support to assist me to take the next steps in managing my MS
- Support to assist me to take a proactive approach to avoid progression of my disease and early management of risk
- Support with continence (assessment, equipment and products)

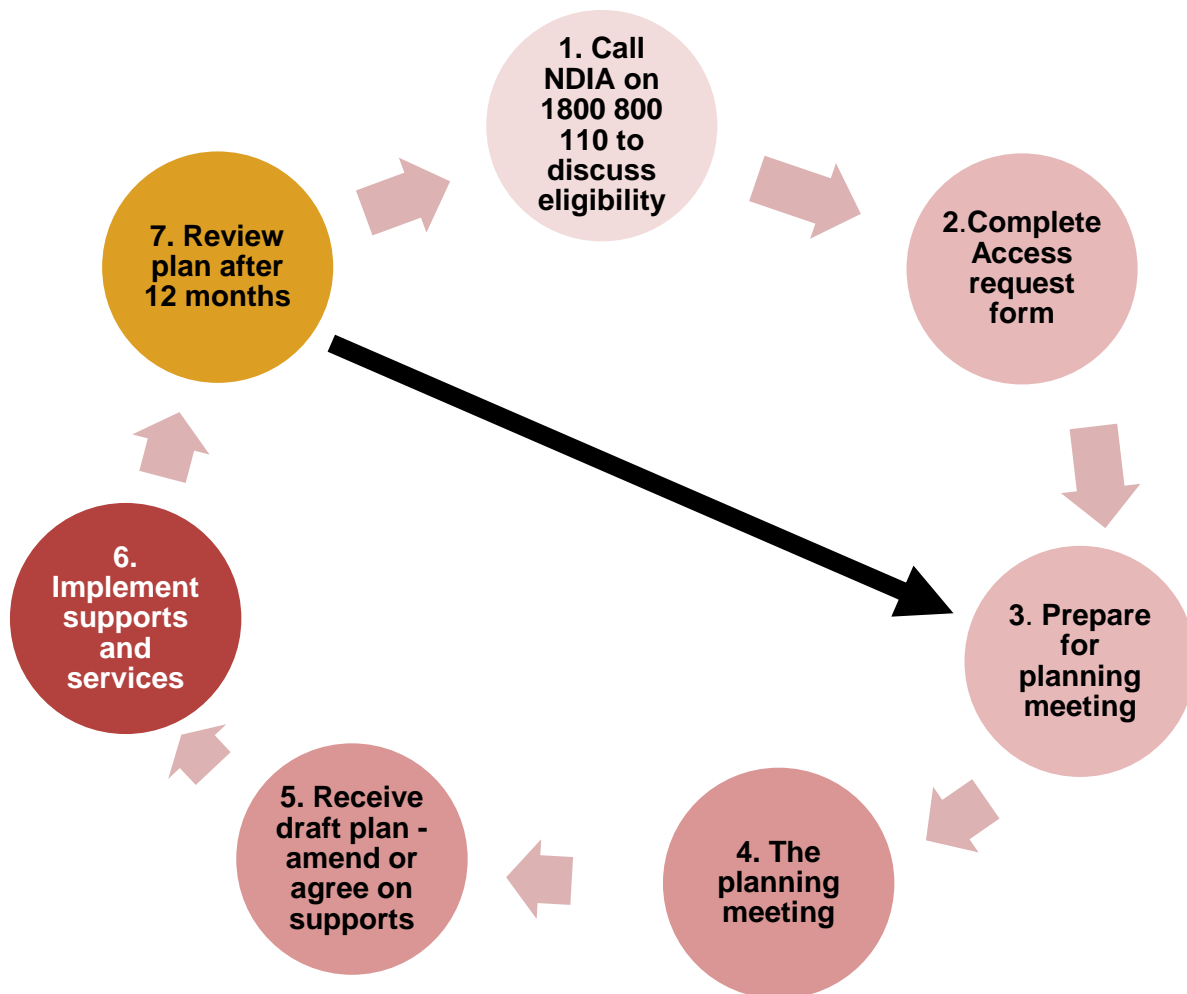
### **Improved Community Access**

- Cooling products so I can still access the community when it is hot
- Access to social support to help address my isolation and loneliness
- Someone to support me to participate in social activities and help me work through difficult tasks (i.e. completing forms, organising appointments, coordinating events)
- Someone to support me with shopping and other community tasks
- Support with maintaining coordination of services and supports
- Transport — maintaining ability to drive or support with transport
- Support for my partner/carer (i.e. so my partner/carer does not have to leave from work to provide support for me)
- Support group (peer, mindfulness, Cognitive Behaviour Therapy)

**OTHER?** (think about what supports might help you achieve your goals)

Comments:

## CHECKING NDIS ELIGIBILITY, NEXT STEPS TO ACCESSING NDIS



- 1.** Call the National Disability Insurance Agency (NDIA) on **1800 800 110** to discuss eligibility for supports/services NDIA.
- 2.** The Agency will post out an **Access Request** form. Your GP or specialist can assist you to complete the Access Request form. If you need assistance at any stage with this form you can call MS Connect on **1800 042 138**. When the form is completed post it back to the Agency. The Agency will then confirm with you if you are eligible for assistance through the scheme.
- 3.** The Agency will post out a **Planning Workbook** to prepare for your planning meeting. You will be asked to think of your needs in terms of your goals and services and supports you need to achieve your goals. If you would like assistance to complete the Workbook please call MS Connect on **1800 042 138**, family and friends can also help you. The **Checklist for people affected by multiple sclerosis** that MS has developed is another

handy tool to help you prepare for your meeting with the Planner. Your **workbook** and **checklist** will be helpful at your planning meeting.

4. The planning meeting can be held at your home, the local NDIA Office or another venue of your choice. At the meeting your Planner will refer to your Planning Workbook which includes ideas about your goals and other supports and services you may need as well as those that you may already have in place. You can request that a family member, friend, advocate or MS consultant also attends the meeting.
5. You will receive your draft plan for your approval.
6. You can now implement your plan. If you think you may need assistance to coordinate your supports and services consider discussing this at your planning meeting.
7. Your plan will be reviewed by you and your Planner on an annual basis; this gives you an opportunity to review and reflect on the outcomes the supports and services you receive have provided, you can request a review at an earlier time if your circumstances have changed.

## **HELPFUL HINTS**

### **GOALS**

What might be a goal e.g.?

To remain employed and care for my children, and continue to live at home as independently as possible

What are the difficulties experienced that reduce capacity to achieve your goals?

### **REASONABLE AND NECESSARY**

NDIA funded supports must be deemed what they call 'reasonable and necessary'.

This is determined using a set of criteria which take into account whether:

- the supports are effective and beneficial and are based on current good practice
- the supports represent value for money
- what is reasonable to expect from family carers, other informal supports, and from community and mainstreams services